





# Improving participation in the NHS Breast, Bowel and Cervical Cancer screening programmes in Cheshire and Merseyside

# **Final report**

An evaluation carried out by NHS Solutions for Public Health on behalf of the Cheshire and Merseyside Cancer Alliance and Champs Public Health Collaborative

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## 1. Overview and key findings

Cheshire and Merseyside Cancer Prevention Steering Group identified improvement in cancer screening performance as a key priority. This was based largely on the association of mortality rates from both cervical and bowel cancer with screening coverage and deprivation, with mortality reducing as coverage increases and deprivation decreases.

Screening participation rates in 2017/18 in Cheshire and Merseyside were:

- 52.8% to 64.3% for bowel cancer screening (target 60%)
- 65.0% to 79.2% for breast cancer screening (target 80%)
- 66.4% to 75.4% for cervical cancer screening (target 80%)

In December 2018 the Screening and Immunisation Team and Cheshire and Merseyside Cancer Alliance supported collaborative stakeholder workshops to discuss screening programmes and identify initiatives to improve screening uptake and coverage.

The workshops identified specific initiatives to improve bowel, breast and cervical uptake and coverage. Screening can do harm as well as good, and so "improving" participation aims to maximise informed decision-making and remove barriers to engagement in NHS screening programmes.

Early-stage cancer is more likely to be diagnosed in people who are screened compared to those diagnosed via the symptomatic route when a late stage cancer diagnosis is more probable. Increased costs in treating and managing late stage cancer diagnosis compared to early stage disease means these interventions may not only deliver sustainable increases in screening participation but reduced secondary care costs over the longer term.

When the Cheshire and Merseyside Cancer Alliance received national funding in early 2019 to be used to improve cancer screening uptake and coverage, three initiatives, identified at the workshops, were selected for support:

- Use of breast and bowel screening coordinators to increase uptake and reduce variation in screening, with a particular focus on underserved groups, by targeting: those due to attend/ complete their first screening; non-responders to screening appointments/ reminders; and people who do not progress to endoscopy for colonoscopy following a positive Faecal Immunochemical Test (FIT) test.
- Implementation of a cervical screening text messaging reminder service through GP
  practices to increase uptake by reminding women to make a cervical screening
  appointment.
- Undertaking community engagement activities to raise awareness of cancer screening and develop an online training package to enable front line community workers to understand the national cancer screening programmes and how they can influence cancer outcomes for the population they work with.

These 3 interventions were targeted across 7 bowel and breast screening programmes and all GP practices in 12 Clinical Commissioning groups in Merseyside Cheshire, Warrington, and Wirral (See Appendix 1).

In tandem with the aim to improve coverage and uptake, the initiatives aimed to reduce variation in cancer screening programmes across Cheshire and Merseyside, focused on population groups who are particularly vulnerable to screening inequalities identified in the PHE Screening Inequalities Strategy (2019 updated 2020) such as people from poorer areas and those from diverse ethnic backgrounds.

### COVID-19

The COVID-19 pandemic and the associated pausing of national screening programmes from March 2020 for three months had a significant impact on the capacity and capability of services to implement the interventions, as did the ongoing pandemic during 2021 and restoration of screening services:

- redeployment of staff and increased levels of staff sickness
- Breast screening programmes often had limited appointments available as infection control procedures reduced the number of women screened during a clinic
- Support for subsequent screening recovery and clearing pandemic backlogs was higher priority for services than improvement in uptake

This contributed to changes in scope and timescale of the screening uptake project which was initially being delivered from 01/04/2020 to 31/03/2021 to an end date of 30/09/22.

#### Breast and bowel screening coordinators

The coordinator posts were fixed term, full time posts, which were hosted by local breast or bowel screening units in NHS Trusts across Cheshire and Merseyside. There were delays in recruiting the Breast and Bowel Screening Coordinators due to COVID-19. Additionally, each screening programme specified when they were ready to have a screening coordinator in post dependent on prioritisation of backlog and staffing issues, so they started at different times. The first screening coordinator started in October 2020. A total of 10 coordinators were recruited to the 8 posts across the time period, only 3 remained at the end of the project.

Originally the coordinator role was focused on working with people who hadn't responded to the offer of screening, to provide information and support and see if that enabled them to participate. As a result of the pressures around COVID-19 and recruitment, the screening coordinators broadened the type of interventions they carried out to 4 types of activities:

- direct contact with people invited for screening and non-responders,
- supporting GP practices with information and help to contact non responders
- community engagement activities
- supporting administration of the units.

For the first two of these activities, where people are directly contacted either by their GP practice or the screening programme, data to evidence improvements uptake was gathered, where possible, as the outcome measure.

It was not possible to set any quantitative outcome measures for community engagement activities. The screening coordinators did capture qualitative experiences of how they carried the engagements and the enablers and barriers.

Two interventions showed a demonstrable change in uptake due to the activities of the screening coordinator. These were:

 Breast screening reminders: a text message was sent at 2 weeks and a telephone call /letter after a further week. This resulted in an estimated 5.9% increase in participation by women invited to book an appointment for breast screening who hadn't responded ≥ 2 weeks following routine invitation • Bowel screening offer follow-up: people contacted by the GP practice who had not taken up the offer of bowel cancer screening when offered in the previous year. This resulted in an estimated 4.4% increase in participation

These interventions were implemented for small cohorts of people eligible for screening and improvements in participation should be viewed with caution when considering wider implementation.

Further interventions included:

- Support for women with additional requirements to attend double fixed appointments for breast screening: there was no clear evidence of an increase in participation when individual patients were tracked. One area did show an improvement in participation for this group, however there were too many possible confounding factors to be confident that the increase was attributable to intervention by the screening coordinator.
- Working with GP practices: this built relationships between primary care and the screening programmes, smoothing communications and enabling practice staff to answer questions from residents with queries about the screening programmes. It was not possible to directly link this with increased screening participation.

Working with Primary Care Network (PCN) leads and cancer leads was felt to be an important starting point to working with GPs. The requirement for GP practices to contribute to an improvement in early cancer detection through the PCN Directed Enhanced Service(DES) means there is more of an incentive for practices to accept support from Screening Coordinators to contact non-responders.

Community engagement activities did increase the visibility of screening programmes in the population, however it was not possible to evaluate the impact of these activities on screening participation. It is always important that local and national health promotion, either universal (for the whole population), or targeted at underserved groups, is undertaken to raise awareness about the signs and symptoms of cancer and participating in screening.

Some Breast and Bowel Cancer Screening Coordinators were engaged in supporting the screening units with their administration processes during times of high staff sickness due to COVID-19. This helped screening coordinators to understand exactly how the screening and assessment pathway functions and improves the quality of the service. However, this will not directly improve participation in screening. It may be that in the future that the roles of screening coordinators combines effective interventions to improve participation in tandem with administrative duties that improve quality improvement.

#### Cervical screening text messaging

The combined impact of the pandemic and navigating unforeseen issues relating to NHSEI information governance and legal issues beyond Champs Support Team control, resulted in being unable to mobilise the cervical text messaging intervention across Cheshire and Merseyside.

#### Community engagement and digital toolkit

It was clear relatively early in the evaluation period that holding community engagement activities during the pandemic was untenable due to a series of lockdowns, social distancing, and a national and local focus on infection control.

Development of a digital online screening toolkit still went ahead with the aim to enable front line community workers to understand the national cancer screening programmes and understand how they can influence cancer outcomes for the population they work with. Due to COVID-19 related delays also, the toolkit is to be launched in January 2023.

Although the cervical screening text messaging workstream did not go ahead, some elements of these were incorporated as part of interventions implemented by the breast and bowel screening coordinators and GP practices they worked with. This included text messaging reminders to people eligible for breast screening to book appointments, texting bowel screening non responders and working with community groups and charities to raise awareness of cancer screening.

#### Scaling up

Using the two interventions that showed a demonstrable change in participation for breast screening (increase of 5.9%) and bowel screening (increase of 4.4%) estimates can be produced of the likely impact on number of additional people screened and referred for diagnostic assessment if the interventions were scaled up.

If screening coordinators focussed on the fifth of practices across Cheshire and Merseyside with the lowest uptake and highest deprivation, they would need to attempt to contact 7,000 women non responders for the breast screening programme and 14,500 non-responders for the bowel screening programme per year.

Scaling up for breast screening, with an estimated investment of around £150,000 per year for screening coordinators (similar to the investment made by the project but focussed only on this one intervention) this may result in an additional 62 women referred for assessment per year costing £2419 per person referred. If all these women were successfully assessed around 14 would be diagnosed with breast cancer.

For bowel cancer screening, if screening coordinators focussed on contacting non responders for this same fifth of the population, this would result in 3 people diagnosed with colorectal cancer or who have a cancer removed during the screening colonoscopy, and around 10 people would be diagnosed with an advanced adenoma. With an estimated investment of around £100,000 per year on screening coordinators (similar to the investment in this project) there would be an estimated additional 37 people referred for diagnostic assessment per year equating to a cost of  $\pounds 2,800$  invested per person referred.

The estimates of the numbers of additional people screened across Cheshire and Merseyside with the implementation of these particular breast screening and bowel screening interventions have considerable limitations. The estimates are based on small sample sizes from 3 or 4 specific GP practices and clinics and although the results illustrate the proof of concept that these interventions are promising, they are not robust enough in their set up, execution and reporting to be used as the sole basis for scaling up this approach and requires further development.

If there is further interest in implementing these interventions it is recommended that a robust pilot project planned specifically for this approach is developed. A standard process for implementation, reporting and follow up of patients could then be put in place for all screening programmes. A focus on GP practices with the lowest uptake and highest levels of deprivation will also be important to maximise the effectiveness of this approach to make most efficient use of the screening coordinator resource whilst addressing inequalities in screening uptake.

#### Barriers to implementing interventions

Feedback from screening coordinators indicates there were some constraints in the activities they could undertake to improve uptake.

• Bowel screening coordinators did not have access to contact details of people eligible for screening so could not directly contact them otherwise it could be seen as coercion.

- Engaging GP practices with the breast and bowel cancer screening process was very difficult at the time and in many cases was not achieved mainly due to practices being focussed on the COVID-19 pandemic and vaccination roll out with reduced capacity.
- There were some difficulties setting up social media pages for the screening programmes within the Trusts to promote screening and community engagement activities due to individual trust policies and governance.

These factors plus the pandemic resulted in a change of focus for screening coordinators. Rather than focussing solely on improving uptake, the roles were also used to support the recovery and restoration of the screening programmes as part of the screening team.

#### Conclusion

Overall, despite difficulties in implementing the Cheshire and Merseyside Cancer Screening programme of work there are some positive outcomes and confirmation of proof of concept about interventions to improve screening participation for breast and bowel cancer screening programmes. These particular interventions could be further piloted and targeted at areas of lowest uptake and highest deprivation to maximise the effectiveness of screening coordinators time and address inequalities in screening uptake.

#### Recommendations

- Develop breast and bowel screening coordinators interventions which demonstrated proof of concept – further development and pilot of text messaging reminder breast screening intervention which demonstrated 5.9% increase in uptake. Further develop and pilot bowel cancer screening intervention following up non-participants who have not take up the offer of a FIT test in the previous year, which demonstrated a 4.4% increase in uptake. Modelling demonstrated that a 2-6% increase in participation would occur.
- 2. **Bowel Screening Coordinators** host in Primary Care Networks where they can be supported by and access available data to follow up on non-participation on a wider scale, in particular those areas and communities which suffer screening inequalities.
- 3. Primary Care continue to build on established relationships with Primary Care Leads and GP practices to support the Direct Enhanced Service (DES) for Primary Care to improve early detection of cancer and empowering the practices to improve the service delivered.
- 4. Barriers to screening gather information collated to inform on the barriers perceived and actual across Cheshire and Merseyside to screening and share with NHSEI Screening Team (North West) to support interventions to reduce and improve uptake of offers of screening with local populations and groups.
- 5. Promote and awareness raising continue to support and engage local populations by the use of newly established NHS trust social media pages screening coordinators have developed highlighting the offers of breast, bowel and cervical screening across Cheshire and Merseyside. Continue to increase visibility of screening programmes through increased engagement activities with communities and businesses.
- Screening Digital Toolkit launch and promote the toolkit, as a resource for front line professionals to utilise i.e. Pharmacists, Community Nursing Teams, Physiotherapists, Occupational Therapists, increasing knowledge on breast, bowel and cervical cancer with a conversational toolkit to support MECC style conversations with patients.

## 2. Evaluation brief and methodology

The funding received by Cheshire and Merseyside Cancer Alliance for the Cancer Screening Improvement programme of work included a proportion for evaluation of each of the three initiatives. The Cheshire and Merseyside Cancer Alliance approached the Champs Public Health Collaborative to lead the programme of work on their behalf in September 2019.

Solutions for Public Health were commissioned by Champs Public Health Collaborative, to evaluate each of the three initiatives and using a process and summative approach to assess impact of the interventions on the cancer screening programmes.

A combined process and impact evaluation using a structured approach was used to assess if the Cheshire and Merseyside Cancer Screening Programme interventions were effective in improving participation in cancer screening programmes and to measure the cost consequences of this (Cheshire and Merseyside Cancer Screening Programme 2019a, 2019b, 2019c).

The evaluation brief outlined the requirements which included:

- A comprehensive review of the current evidence relating to each element
- A logic model covering the key elements and interactions of each workstream
- The purpose and scope of the evaluation, including the evaluation questions
- Implementation of the whole process and reporting for each workstream including:
  - Success in achieving the targeted outcomes
  - Cost effectiveness
  - Value for money
  - Modelling the potential impact on services
  - Perceptions of stakeholders and participants of the screening programme.

In addition the evaluation needed to take into account any reduction in variation in the people who participated in cancer screening programmes by looking at how the initiatives focussed on those that are more vulnerable to screening inequalities including:

- People living in poorer areas
- People with a learning or physical disability
- Black, Asian or people from other ethnic minority groups
- Lesbian or bisexual women
- Men who are less likely to be screened than women.

An evaluation plan outlining the evaluation logic model, questions and methodology was developed during January to April 2020. This coincided with the start of the COVID-19 pandemic when all cancer screening programmes were paused for three months from March 2020. In response the evaluation methodology for each of the three initiatives was modified to take into account delayed start dates and the uncertainty about how and what interventions would actually be implemented. Further details on the evaluation plan and methods are set out in Appendix 2.

Evaluation activities included:

• Evidence review – a rapid evaluation of published and unpublished literature related to the chosen interventions was undertaken as part of the initial scoping work. The results of the evidence review are summarised in the findings and are set out in Appendix 3

- Modelling potential impact on services based on the most recent figures about prepandemic cancer screening uptake (2019/20) a range of trajectories were developed to model the impact on breast and bowel screening services of improved participation of 2%, 4% and 6%. Trajectories based on 4.8% and 5.9% were used for the cervical screening initiative based on the outcomes of recent pilot studies in London using a similar approach
- Evaluation questions and logic models
- Tailored evaluation approaches by intervention type quantitative and qualitative elements including data collection, semi-structured interviews, review of routinely published national data.

### 3. Intervention 1: Bowel and Breast Screening Coordinators

The intention of employing screening coordinators in each of the Cheshire and Merseyside NHS Breast and Bowel screening programmes is so they can implement interventions to improve participation in the bowel and breast cancer screening programmes. The project initiation document detailing the activities of the screening coordinators stating that they:

'....will target those who are due to attend/ complete their first screening, non-responders to screening appointments/ reminders and people who do not progress to endoscopy for colonoscopy following a positive Faecal immunochemical Test (FIT) test' (Cheshire and Merseyside Cancer Screening Programme 2019a).

#### Literature review: Bowel and breast screening coordinators

The search for published evidence identified relevant studies on the effectiveness of screening coordination to improve the participation in breast and bowel cancer screening. No additional studies were found by a search for grey literature.

Three UK studies included one RCT concerning bowel screening conducted in Tyneside (McGregor et al 2019) and two pilot studies concerning breast or bowel screening conducted in London (Graham et al 2014; Raime et al 2012). A French RCT and cost-effectiveness analysis on bowel cancer screening was also identified (De Mil et al 2018).

All studies targeted non-responders/ non-attenders for screening with patient navigators (equivalent role to screening coordinators) primarily attempting to contact patients by telephone. The French RCT demonstrated an improved uptake of approximately 3% for faecal occult blood test amongst non-responders for patient navigation compared to usual care. The UK RCT did not demonstrate a benefit of patient navigation above usual care for bowel scope screening. However, the design and context of the RCT may have limited its ability to demonstrate effectiveness of the intervention.

The two UK pilot studies did not include a comparator. Raime et al (2012) reported that 34% of participants received a mammogram and Graham et al (2014) reported that 19% of participants completed Faecal Occult Blood (FOB) Test following a patient navigator intervention.

The studies varied in size and there was some differences in the patient navigator interventions. Only the French RCT provided evidence for the extent to which patient navigation may increase uptake above usual care.

#### Modelling trajectories: Bowel and breast screening coordinators

For both bowel and breast cancer screening an estimation of the impact of the screening coordinators initiative was made by assuming that screening participation may increase by between 2% to 6%. These percentages have been chosen based on the results of a pilot patient

navigator intervention carried out as part of the breast screening programme in Knowsley. The highest increase in participation for a practice was around 6%.

Tables 1 and 2 show the bowel and breast screening data for units in Cheshire and Merseyside using the baseline figures for 2019/20 and estimating the impact of an increase of 2%, 4%, and 6% assumed to be due to the activities of the screening coordinators within these units. These estimates include the additional number of people screened and referred for diagnostic assessment.

For bowel cancer screening the national acceptable uptake rate is  $\geq$  52.0% and the achievable target is  $\geq$  60.0%. Around 2%<sup>1</sup> of people participating in bowel cancer screening will receive a positive result and be referred for diagnostic assessment. In Cheshire and Merseyside screening uptake ranged from 58.5% of those for the Liverpool and Wirral unit, 64.2% for the Cheshire unit and 60.7% in the Merseyside and North Cheshire unit. If the screening coordinators activities increased uptake by 2% an additional 1193 to 1655 people would be screened per year by unit which equates to an additional 27 to 33 people referred for assessment per year. With a 6% increase in uptake annually an additional 3578 to 4966 people would participate in screening resulting in an additional 71 to 99 people referred for assessment.

# Table 1: Estimates of the impact of screening coordinators on bowel cancer screeninguptake in Cheshire and Merseyside bowel screening units based on the number of peopleinvited and participating in screening in 2019/20\*

Bowel screening unit	Estimated people Screened (uptake %)	Estimated additional people screened per year	Estimated number referred for Assessment (2%) <sup>1</sup>	Estimated Additional people referred per year
Cheshire 67,330 invited	43,207(64.2%)*	N/A	864	N/A
2% uplift	44,554	1347	891	27
4% uplift	45,900	2693	918	54
6% uplift	47,247	4040	945	81
Liverpool and Wirral 59,634 invited	34,904 (58.5%*)	N/A	698	N/A
2% uplift	36,097	1193	722	24
4% uplift	37,289	2385	746	48
6% uplift	37,675	3578	754	71
Merseyside and North Cheshire 82,772 invited	50,272 (60.7%)*	N/A	1005	N/A
2% uplift	51,927	1655	1039	33
4% uplift	53,583	3311	1072	66
6% uplift	55,238	4966	1105	99

\*Figures from NHS Screening Programmes: KPI reports 2019 to 2020; https://www.gov.uk/government/publications/nhs-screening-programmes-kpi-reports-2019-to-2020

For breast cancer screening the national acceptable uptake rate is  $\geq$  70.0% and the achievable target is  $\geq$  80.0%. In Cheshire and Merseyside screening uptake ranged from 64.1% for the Liverpool unit and 75.3% in the Warrington, Halton, St Helens and Knowsley Breast Screening Programme. If the screening coordinators activities increased uptake by 2% an additional 309 to 950 people would be screened per year by screening unit resulting in an additional 14 to 27

<sup>1</sup> Navarro M, Nicolas A, Ferrandez A, Lanas A. Colorectal cancer population screening programs worldwide in 2016: An update. World J Gastroenterol. 2017 May 28;23(20):3632-3642. doi: 10.3748/wjg.v23.i20.3632. PMID: 28611516; PMCID: PMC5449420

people referred for assessment per year depending on the size of the unit and their 2019/20 assessment referral rate. With a 6% increase in uptake an additional 927 to 2850 people would participate in screening resulting in an additional 36 to 94 people referred for assessment.

Table 2: Estimates of the impact of screening coordinators on breast cancer screening uptake in Cheshire and Merseyside breast screening units based on the number of women invited and participating in screening in 2019/20\*

Breast screening unit number invited and % potential uplift	Estimated women Screened (uptake %)	Additional women screened per year	Referrals for Assessment per year(%)	Estimated additional women referred per year
Crewe 15,454 invited	10,816 (69.9%)*	N/A	398 (3.7%)*	N/A
2% uplift	11,125 (71.9%)	309	412	14
4% uplift	11,434 (73.9%)	618	423	25
6% uplift	11,743 (75.9%)	927	434	36
East Cheshire & Stockport	17,090 (68.3%)	N/A	758 (4.4%)	N/A
25,029 invited				
2% uplift	17,591 (70.3%)	500	774	16
4% uplift	18,091 (72.3%)	1000	796	38
6% uplift	18,592 (74.3%)	1500	818	60
Liverpool 47,485 invited	30,454 (64.1%)*	N/A	1072 (3.5%)*	N/A
2% uplift	31,404 (66.1%)	950	1099	27
4% uplift	32,353 (68.1%)	1900	1132	60
6% uplift	33,303 (70.1%)	2850	1166	94
Warrington Halton, St Helens and Knowsley 25,573 invited	19,248 (75.3%)*	N/A	707 (3.7%)*	0
2% uplift	19,759 (77.3%)	511	731	24
4% uplift	20,271 (79.3%)	1023	750	43
6% uplift	20,782 (81.3%)	1534	769	62
Wirral & Chester 27,591 invited	20,087 (72.8%)*	N/A	761 (3.8%)*	0
2% uplift	20,639 (74.8%)	552	784	23
4% uplift	21,191 (76.8%)	1104	805	44
6% uplift	21,742 (78.8%)	1655	826	65

\*Figures from NHS breast screening programme 2019-20 <u>https://digital.nhs.uk/data-and-</u> information/publications/statistical/breast-screening-programme/england---2019-20

#### Evaluation support to screening coordinators

At the outset of the breast and bowel cancer screening coordinator project, the interventions to be implemented by coordinators were not fully defined by the original project initiation document (PID) (November 2019).

Interventions were expected to focus on engagement with people who had not responded to an invitation to participate in the cancer screening programmes however, as each screening unit services a different population with different diversity and needs, ultimately activities were dependent on the priorities of each NHS Trust Screening Manager in order to define their needs and achieve greatest impact for their local population.

A role matrix was developed by the Programme Manager and Screening Programme Managers detailing interventions to support this new role in improving the uptake of screening and reducing inequalities.

Before screening coordinators could be recruited the pandemic took hold and it wasn't until November 2020 when the first screening coordinator was in post with the next role filled in February 2021. The context of the pandemic changed how the role of the screening coordinators was perceived and a range of interventions different to those outlined by the PID were developed. These included

- The screening coordinator working collaboratively with GP practices to support the improvement in uptake and coverage
- Encouraging GP practice staff to acknowledge the importance of their role in endorsing the screening programme
- Use of data and reports to identify areas with the lowest uptake and areas of inequality in screening and support targeted activity
- Providing effective health promotion support to raise awareness of screening and support improvement in uptake and coverage
- Working collaboratively with a range of stakeholders including, but not limited to, Champs Public Health Collaborative, NHSE/I, GP Practices and Leads, CRUK, Action on Cancer in Cheshire, LA Public Health Teams

In order to help the screening coordinators to choose and plan interventions, and how to collect data to show if they were making a difference, SPH provided the following support:

- Interviewed all the screening managers prior to the screening coordinators being in post to understand how the service may want to use the screening coordinator and offer support
- Interviewed all screening coordinators in the early stages of their appointment to talk through their planned interventions and how they might measure them to see if they have made a difference to uptake.
- Developed a template for the screening coordinators to report information about all interventions implemented on a monthly basis (Appendix 4)
- Interviewed screening coordinators every 2 to three months following the initial conversation to check progress on interventions, suggest ways of solving problems and offer support
- Collated data of breast and bowel cancer screening uptake for 2019/20 by GP practice including index of multiple deprivation score and calculated uptake trajectories of 2%, 4% and 6%. This was sent to screening coordinators so they could target practices with their interventions in the most deprived areas and those with the lowest uptake
- Offered ongoing support to the screening coordinators about implementing effective interventions and how to measure if they made a difference.
- Delivered evaluation session for screening coordinators to understand the purpose and scope of evaluation for interventions they implement

Key question 1: How has the screening coordinator initiative been implemented?

#### Context

The plan for engaging screening coordinators was that each breast and bowel screening service would receive funding to cover the cost of employing an AfC band 4 cancer screening coordinator who would be based within each of the screening services (job description set out in Appendix 5).

This was at the very beginning of the COVID 19 pandemic and by March 2020 both cancer screening programmes had been paused throughout the country. Communication between the project manager of the Cheshire and Merseyside Cancer Screening Programme and each of the screening managers within the Trusts continued and agreements were made about recruitment of the screening coordinators.

Stakeholder meetings took place prior to development of the roles, with membership from all Cheshire and Merseyside Trusts and Local Authorities, where the banding of the roles was agreed and the duties and responsibilities defined and agreed. The role was a fixed term 12-month position which was extended, due to the COVID-19 pandemic, to 2 years with additional funding from the Cheshire and Merseyside Cancer Alliance.

All trusts, where NHS screening units were located signed up to participating in the project and hosting a coordinator, although a few concerns were expressed afterwards including: the AfC grade of the coordinators being too low; the 12-month project timeline being too short (which was extended to mitigate for the pandemic); and that NHS Bowel Screening Centres within Trusts could not directly contact people eligible for screening.

By June 2020 the national cancer screening programmes had been re-started but there was a significant backlog of people that needed to be invited so there was reluctance in some local screening units who had agreed to host, to add pressure by employing a screening coordinator due to staffing capacity issues. The first interviews with Screening Programme Managers of the units were carried out in October/November 2020 when the first Bowel Cancer Screening Coordinator was employed. The contracts for the screening coordinators had initially been for a year but these were extended until September 2022 to mitigate the delays due to the pandemic.

#### **Recruiting screening coordinators**

Following delays in recruitment due to screening services recovering from the challenges of the pandemic, it took a while to fill the 8 screening coordinator posts (Table 3).



# Table 3: Bowel and breast screening units and month and year screening coordinators started and finished in post

ECS Br – East Cheshire and Stockport breast screening programme; WHSHK BSP Warrington Halton St Helens and Knowsley breast screening programme; LSK BSP – Liverpool, Sefton, and Knowsley Breast Screening Programme; WWC BSP – Wirral and West Cheshire Breast Screening Programme; LSK BCSP - Liverpool, Sefton, and Knowsley Bowel Screening Programme; WKL BCSP – Wirral, Knowsley, and Liverpool Bowel Screening Programme; Cr BCSP – Crewe Bowel Screening Programme

There is a year between the start date of the first screening coordinator at the end of October 2020 in the Crewe bowel cancer screening service and the start date of the last screening

coordinator in post in the Wirral and West Chester breast screening programme (November 2021).

With an extension of the screening coordinator contracts until September 2022 this meant that the roles were funded for between 11 and 22 months. No screening coordinator was in post for the full 2 year period of the evaluation. The posts were unfilled at times due to the pandemic and the recovery and restoration of the individual screening units. Additionally as the posts were fixed term people left for permanent posts. A total of 10 were recruited to the 8 posts across the period and only 3 remained at the end of the project.

Once screening coordinators were in post, they received a training session organised by the Champs Support Team and delivered by a Screening Manager at Warrington CCG - Cancer Screening Ambassador course aimed at those with little knowledge of cancer. It was split into three sessions about understanding cancer, cancer screening and the role of a cancer ambassador. The feedback from the screening coordinators was that it was very helpful orientation for the role.

In addition screening managers would agree other on the job training, for example in how to use the National Breast Screening System (NBSS) or the Bowel Cancer Screening System (BCSS) in order to access information about people they were planning to contact.

As the screening coordinator roles were being filled from October 2020 onwards those in post were working with the following aspects of their role:

- Understanding the cancer screening landscape in their patch and how the pandemic had changed the service from 'business as usual' to 'recovery' and 'restoration' phases
- Liaising with the other screening coordinators in post as part of the project
- Working with the Cheshire and Merseyside Cancer Screening Programme Manager to fulfil the project scope and report progress at monthly network meetings
- Working with their screening manager to understand how they wanted the role to be shaped
- Developing interventions for which there was a clear rationale that would lead to an uptake of screening in some or all groups invited to participate
- Developing interventions which supported the promotion and visibility of breast and bowel cancer screening within the catchment population of the service.

#### Feedback from screening coordinators about their role

Feedback from screening coordinators indicates they were constrained in the activities they could undertake to improve uptake. Breast screening programmes often had limited appointments available due to the COVID-19 pandemic as infection control procedures reduced the number of women screened during a clinic and there was a pandemic backlog to clear, so it was not helpful to try and improve uptake in this context.

Bowel screening coordinators did not have contact details of people eligible for screening so could not directly contact them. Engaging GP practices with the breast and bowel cancer screening process was very difficult and in many cases was not achieved partly due to practices being focussed on the COVID-19 pandemic and then vaccination roll out. There were often difficulties setting up social media pages for the screening programmes within the Trusts to promote screening and community engagement activities were curtailed during pandemic lockdown periods.

Some screening coordinators found it more rewarding to develop community engagement activities during 2022 as pandemic restrictions lifted. However, the direct impact on screening participation cannot be evaluated as an outcome of these interventions. This is because there is

no direct connection between those who engage in the community and those invited for screening by a particular screening programme. There are many confounding factors that cannot be controlled which means any change in screening uptake cannot be attributable to community engagement. In full research projects individual people can be contacted at the outset of the intervention and tracked and followed up to see if they participated in screening when they are next invited (up to 2 to 3 years later) and asked whether the community engagement process influenced their decision making. These types of studies were not feasible as part of this evaluation.

In addition to external factors impacting on the breast and bowel screening coordinator workstream, screening coordinators reported that they didn't always feel supported, by the screening programme and project team. The project team did deliver a wraparound provision of support to the group of screening coordinators, to provide induction, training, upskilling, protected time to meet together once a month, facilitated working with primary care networks, and support with day-to-day queries. However, there was still considerable frustration for screening coordinators at the barriers to implementing activities that would improve uptake. Part of the role was to identify these barriers and report back and some are already known barriers such as bowel screening teams being unable to access data.

The screening coordinators felt that, in some circumstances, the AfC grade 4 level role didn't have the leverage to persuade GP practices and other organisations engage with the project.

Some felt isolated as although they often worked together on some interventions, they were based in separate Trusts and each screening programme had a different view about what they wanted from the screening coordinator role (which would have been discussed at interview stage). Some screening managers were supportive and took an active role in guiding the screening coordinators whilst others were less engaged.

#### Views of the screening managers

Table 4 below details the key themes emerging from the interviews with the screening managers and coordinators

Table 4: Views of breast and bowel screening managers			
Theme	Comment		
Planned Screening coordinator role	For breast screening, managers planned that screening coordinators will follow up on women not attending for screening. It is also important for them to liaise with GP practices in the community to actively promote breast screening uptake. Currently GP practices are all sent an information pack about breast screening, but ideally this would be followed up by a face-to-face visit. Capacity issues mean that this does not happen currently. There may also be other community groups that the screening coordinator could engage with that would help to encourage uptake.		
	Bowel screening managers felt that promotion of the programme and linking in with GPs to talk about uptake targets and non- responders was important, setting up stands and posters with an emphasis on underserved groups. The role would involve linking in with businesses, local support groups, learning disabilities and ethnic minority groups e.g., Polish, and Slovakian groups.		
	Bowel screening coordinators would visit other programmes and the hub to share and learn, and link deprivation data by practice with uptake via Fingertips interface. They will be trained as an administrator and sit with programme team.		
	For bowel screening, managers had concerns that as the screening unit does not have access to data of people sent invitations, screening coordinators could not directly contact non responders and to do so would be considered coercion. Contact would have to be made via primary care. Screening coordinators could support Specialist Screening Practitioners (SSPs) getting patients through system after positive test results e.g., contacting people who didn't attend colonoscopy, and ensure all paperwork was complete.		
	There was some concern that the role may overlap with the community engagement initiative work.		
Banding of screening coordinators	Some screening managers felt the role should be banded higher than an Admin and Clerical band 4 especially when people in equivalent roles from elsewhere were in a higher band. Some thought a band 4 role was not senior enough to effect change and they did not have the leverage to persuade GP practices and other organisations to work with them.		
	(Note: The Screening Coordinator roles were developed with the Screening Programme Managers at the start of the project in 2019 and agreed to the banding and duties and responsibilities, this opinion may have changed as the role progressed)		

Length of post	Some screening managers thought 12 months was too short a time for the screening coordinator post to be able to make a difference in screening uptake. For breast screening all women eligible to be screened by the unit are called over a 3 year period so with a 12 months post only one third of GPs will be included. [Note: With the continuing impact of COVID-19 the Community Engagement project was curtailed by Cheshire and Merseyside Screening Programme and funding was re-allocated to the Bowel and Breast Screening Project resulting in an extension of all Screening coordinators roles until September 2022.]
Impact of COVID 19 pandemic	For breast screening units, recovery following the pause in the programmes will take a long time. Changes in the programme were agreed with the national team to help recovery. This includes inviting women to make an appointment for screening rather than sending a fixed appointment. This aims to reduce the number of women who do not attend (because they have made an appointment so are invested in the process) but it may also result in lower participation.
	One screening manager said that as of November 2020 the screening coordinator role would not be helpful as set out in the job description because there were other more essential roles in the team which were needed as the service was in recovery from the pandemic (in addition to pre-pandemic challenges with meeting uptake targets).
	(Note: the emphasis of the role changed during the pandemic to support with restoration of the screening programmes and to improve not increase uptake, so those that are being invited to attend appointments support to attend where capacity allowed)
	Bowel screening programmes were trying to clear the backlog but it was slow and there was a lack of staff for core activities. Virtual rather than face to face assessments had been put in place for SSP clinics.
	Both breast and bowel screening teams were struggling due to staff being off sick with COVID 19 or needing to isolate following contact with a positive case or re-deployment to cover other areas.

One important point is that bowel screening managers voiced the opinion that screening coordinators would not be permitted to contact non responders directly and would not have access to data about non responders. However, the first six points of the key duties and responsibilities of the (joint) screening coordinator job description is about contacting, supporting or compiling data about non responders (Appendix 5).

Having separate job descriptions for bowel and breast screening coordinators was discussed at the outset of the project however it was agreed to proceed with a joint role description.

Breast and Bowel Screening Managers developed and signed off the job specification and stated 'where appropriate/relevant' against each key duty/responsibility. This contrast between the key aims of the role and what the bowel screening coordinators could actually do as part of their job was a constraint on their potential effectiveness to improve uptake at the outset of the project.

(Note: this is an historical barrier to bowel screening, not specific to this role).

Alternatively, in order to align the Bowel Cancer Screening Coordinators activities closely with the aims of the PID, it may have been helpful for bowel screening coordinators to be based in a PCN rather than the NHS Bowel Screening Centres. Refreshing the PID so the goal of the workstream wasn't solely to improve uptake when it was clear before screening coordinators were in post that this would be problematic due to the pandemic could have been an alternative approach.

(Note: The aim of the role was refreshed in light of the pandemic to support with recovery and restoration in addition to ensuring that those invited for screening are supported to attend. The objectives were clarified to Screening Programme Managers with hosting agreement documents signed each year by the trusts involved. PCN's were being established from July 2019 onwards and some not in evolved fully in Cheshire and Merseyside at commencement of the project, alignment of the Bowel Cancer Screening Coordinators with PCN's is a recommendation from the project)

# Key question 2: Is the screening coordinator initiative on track to achieve the goal of improving uptake in underserved groups?

#### Context

When screening coordinators took up their posts they had some initial ideas about types of activities to improve uptake. Many of these activities were directly impacted by the pandemic lockdowns, the pressures on primary care and on their own screening services. Working together, the screening coordinators developed a series of interventions which they implemented during and after lockdowns. The screening coordinators must be congratulated on their dogged persistence in putting interventions in place in the face of extremely challenging circumstances.

Interventions: Bowel and breast screening project

Overall the screening coordinators have carried out 4 types of activity. These include:

- Direct engagement with people invited for breast screening or invited for a bowel diagnostic assessment by phone, letter/card, text message or survey request
- Engagement with PCN leads and practices to:
  - Provide information to both administrative and clinical staff prior to women in their practice being called for breast screening so they can easily respond to queries
  - Work with practices to identify breast and bowel screening non responders and contact them to offer information, support and the opportunity to participate or understand the reasons for non-participation

- Community engagement, such as:
  - Presence on social media
  - Contacting key groups in the community where the target population is likely to meet, providing health promotion materials such as posters, leaflets and content for webpages aimed at the target group
  - Visiting high foot fall areas for example libraries and shopping centres
  - Visiting particular groups such as those at the homeless shelter, people in prison and other groups such as the Women's Institute to present information
- Administrative role such as improving breast screening contact data or supporting the bowel cancer screening specialist screening practitioner to improve the service.

Tables 5, 6, 7 and 8 outline approaches for each of the four types of interventions. A brief description of the interventions, and of the strengths and challenges of the approach were gathered from interviews and monthly reports. Evaluation approach and brief outcomes are presented for some interventions where available.

Case studies of examples of eight interventions involving direct contact, engagement of GP practices and community engagement are included in the Appendix 6. The administrative support interventions were not directly designed to improve uptake but rather the quality of the service so do not feature in the case studies.

Screening interventions	Strengths and challenges	Evaluation measure and outcome
Breast Cancer Screening		
Breast screening direct contact 1: Women invited to	<ul> <li>Strengths:</li> <li>Direct engagement by text message with women who don't make an appointment to be screened within 2</li> </ul>	<b>Evaluation:</b> Number of women booking appointment before and after text message and telephone call/letter for each clinic.
book an appointment for screening who hadn't responded ≥ 2 weeks. Text		<b>Outcome:</b> Of 306 women invited to book an appointment for screening during November 2021:
message sent at 2 weeks and	weeks of receiving invitation	• 141(46%) booked after a first invitation,
week	Challenges:	Of 165 women contacted after the routine invitation:
	<ul> <li>Sometimes appointments are not available and text messages are paused</li> </ul>	<ul> <li>71 (43%) booked following a text message 2 weeks after the first invitation</li> </ul>
	<ul> <li>Manual extraction of phone numbers from NBSS is time consuming and likely to be prone to error. It is likely that an IT solution could be implemented for this process.</li> </ul>	<ul> <li>49 (30%) booked following a phone call 1 week after the text message</li> </ul>
		<ul> <li>45 (15%) of those invited did not participate in screening whilst 85% of those did book into a clinic</li> </ul>
		It is estimated that this translates into a 5.9% increase in participation (see case study 1)
Breast screening direct	Strengths:	<b>Evaluation:</b> Number of women re-booking when contacted following
a screening appointment but did not attend. Phone call	<ul> <li>Helps to understand why women DNA</li> </ul>	Outcome: During November 2021 of 57 women contacted by telephone:
about reason for DNA and	<ul> <li>reason for DNA and</li> <li>o re-book. Also women</li> <li>contacted who DNA'd</li> <li>Gives women another opportunity to book an appointment</li> </ul>	• 28 (49%) no answer
were contacted who DNA'd		• 19 (33%) screening coordinator left a message

# Table 5: Interventions using direct engagement with people invited for screening

from a booked double	Challenges:	• 4 (7%) women rebooked
appointment	<ul> <li>It isn't clear whether the effort to call women translates in improved uptake</li> <li>Manual extraction of phone numbers from NBSS is time consuming and likely to be prone to error. It is likely that an IT solution could be implemented for this process</li> </ul>	<ul> <li>2 (3%) people were unwell</li> <li>1 (2%) person went to wrong clinic site, declined to rebook</li> <li>1 (2%) person was on holiday</li> <li>1 (2%) person hung up</li> <li>1 (2%) number won't connect</li> </ul>
		<ul> <li>For women who had a double appointment there were 11 DNAs in August, 4 in September and 11 in October 2021. The reasons for not attending include:</li> <li>Forgot</li> <li>Ill Health</li> <li>Holiday</li> <li>Transport issues</li> </ul>
Breast screening direct	Strengths:	Evaluation: Number of women re-booking when contacted following
contact 3: To contact all women who DNA to determine reason and offer to re-book	all • Helps to understand why women DNA	DNA. Outcome: At 1 GP surgery 66 (40%) of 166 women were contacted:
	Gives women another opportunity to	<ul> <li>18 (27%) had already rebooked appointment</li> </ul>
	book an appointment	<ul> <li>26 (39%) rebooked due to screening coordinators call</li> </ul>
	Challenges:	
	<ul> <li>It isn't clear whether the effort to call women translates to improved uptake</li> </ul>	

Breast Screening direct contact 4: To contact women who had been invited for screening for the first time (prevalent cohort) but who hadn't attended to offer to rebook and determine the reason for not attending

- direct Strengths:
  - The prevalent group of women are more likely to DNA than those that have been invited before
  - Gives women an opportunity to ask questions and re-book appointment

#### Challenges

 People don't answer the phone – many are under retirement age so likely to be at work

**Evaluation:** Outcome of attempting to contact prevalent women who DNA:

Outcome	Number (%)
No answer	40(37%)
Appointment re-booked before the call	23(21%)
Appointment re-booked during the call	14(13%)
Opted out of screening (temporary)	13(12%)
Unable to contact	13(12%)
Ceased from screening	4(4%)
Under care of Breast Cancer Service	1(1%)
Total	108

At least 34% of women who did not attend breast screening, re-booked their appointment either of their own volition (21%) or during the call with the screening coordinator(13%). It is unclear how many women who did not answer the call may also have re-booked their appointment.

Breast screening direct Strengths: contact 5: Text reminders sent 1 week and 1 day prior to a breast screening appointment Direct contact them of app

Direct contact with women to remind them of appointment and ask to inform unit if they need to cancel

**Evaluation:** To compare DNA rate prior to text reminders and after they had been implemented. DNA rates were around 5% in both Macclesfield and Stockport before initiative.

No improvement of DNA rates which remained similar at 4%-5%.

	<ul> <li>Mobile numbers not available for a proportion of women</li> <li>Manual extraction of phone numbers from NBSS is time consuming and likely to be prone to error. It is likely that an IT solution could be implemented for this process</li> </ul>	There will always be a proportion of w attend appointments due to changes what minimum DNA rate could be rea	romen who fo in circumsta asonably ach	orget, or are un nces and it is n ieved.	able to unclear
Breast Screening Direct contact 6: Women who require a double fixed appointment contacted prior to appointment and if DNA	<ul> <li>Women contacted and appointment booked at the best time for them. Any queries answered and support offered.</li> </ul>	<b>Evaluation:</b> Breast screening attendation of the contact calls with those who Discontact call	ance followin NA med appoint	ig calls and out	tcomes
	<ul> <li>Better understanding about the issues facing women requiring a double appointment</li> </ul>	Women invited for longer timed	Number	%	]
		appointments			_
		Attended	223	68%	
		Did not attend	103	32%	
	Total	306	100		
		Contact calls to DNAs	103		
		Contact calls to DNAs answered	14		
		Rebooked appointments	14		
		Attended re booked appointment	7		
		DNA rebooked appointment	5		
		Cancelled	1		
		Rebooked appointment	1	-	
		outstanding			
		A small proportion (14%, n=14) of successfully contacted, and of th appointment. Of the 7 women who re-further appointment.	women who nose 50% booked 5 (7'	did not atten (n=7) rebook 1%) did not atte	d were ed an end this

screening Breast contact 7: All women with who double fixed reauire а appointment (e.g., women with LD, physical disabilities, or need an interpreter etc). Women contacted before invitations sent to book appointment and again two days before appointment to check other support needed.

direct Strengths:

- Women contacted and coded correctly
- Better understanding about the issues facing women requiring a double appointment
- Appointments made at a convenient time for women rather than fixed appointment being made

#### Challenges

 A time consuming process and may require conversations with carers or other family members to explain breast screening prior to making an appointment **Evaluation:** Proportion of women attending appointments of those invited and if possible proportion who attended last screening appointment

**Outcome:** This intervention was implemented in March 2021 by one Trust and at this time the country was still in pandemic lockdown:

Double fixed appointment uptake:

- February 2021 53%
- March 2021 73%
- April 2021 66%
- May 2021 68%
- June 2021 68%
- July 2021 75%
- August 2021 65%
- September 2021-93%
- October 2021 82%

Breast screening direct S contact 8: Women who require double appointment slots in June 2022 (e.g., women with LD, physical disabilities, or need an interpreter etc). are

contacted before invitations

sent to book appointment

direct Strengths

- Women contacted and appointment booked at the best time for them. Any queries answered and support offered.
- Better understanding about the issues facing women requiring a double appointment

Challenges

**Evaluation:** Proportion of women contacted in June 2022 who attended their appointment this round and the previous round, compared to those not contacted in June who attended their appointment this and the previous round.

**Outcome:** Of 35 women contacted 30 (86%) attended this screening round and 28 (80%) attended the previous round. Of the 66 women not contacted in June 54 (84%) attended this screening round compared to 52 (81%) who attended the previous round. There seems limited scope for increasing uptake with this particular cohort of women offered double appointments.

	<ul> <li>A time consuming process and may require conversations with carers or other family members to explain breast screening prior to making an appointment</li> </ul>	<ul> <li>For this Breast screening programme, at the screening site chosen in June 2022, there is already a high proportion of women requiring double appointments who are attending screening prior to an intervention being implemented.</li> <li>Reasons for declining screening include: <ul> <li>Too unwell</li> <li>Under care for breast or other cancer</li> <li>Distressed and could not tolerate the process</li> <li>Transport difficulties</li> <li>Bad experience during previous round</li> <li>Away during screening period</li> <li>Focus on other health concerns</li> <li>Unable to move into correct position for mammogram</li> </ul> </li> </ul>
Breast screening direct contact 9: Survey of women who attended assessment clinic to ask for feedback to improve service	<ul> <li>Strengths:</li> <li>Useful feedback from routine patient survey</li> <li>High uptake when link to survey was texted to women</li> <li>Challenges:</li> <li>Does not directly improve</li> </ul>	<b>Evaluation:</b> survey results <b>Outcome:</b> Around 624 people responded to the survey in one breast screening service. Questions were not about screening but rather about their experience of the breast assessment clinic process such as the helpfulness of the information and website, access to the clinic and parking, and experience of the procedures.
	participation in screening but will help improve quality of service	

A further survey of assessment clinic attendees by a second Breast Screening Unit had a response of 162/200 questionnaires.

Breast screening direct contact 10: Women invited for last time for screening given card so they can self refer in 3 years' time	<ul> <li>Strengths</li> <li>Easy to identify women having their last invited screen and give them a card</li> <li>Challenges</li> </ul>	<b>Evaluation:</b> Reflections of screening coordinator Cards handed out to women with information about how to self-refer. Screening coordinators reflected that the reminder cards and information was welcomed by the women.
	<ul> <li>Women over the age of 71 are not included in uptake figures as this isn't the target age group</li> </ul>	

### Table 6: Interventions involving engagement with GP practices

Intervention	Strengths and challenges	Evaluation measure and outcome
Breast Cancer Screening		
Breast screening GP engagement 1: Presentation given at GP practices whose women were due to be called for screening to engage with staff including admin staff	<ul> <li>Strengths</li> <li>Building relationships with GP practices near the time when their women are called for screening is helpful to remind admin and clinical staff how the breast screening programme works, what changes there have been since the previous round and the information about women that may be requested by the Breast Screening Unit that GP practices can provide.</li> </ul>	<ul> <li>Evaluation: Feedback from GP practices visited and reflections of screening coordinator</li> <li>Outcome: GP practices have been visited by screening coordinators and practices, especially practice managers and the administration team have been enthusiastic and engaged. Additional posters have been provided and the screening coordinator ensures the practice has the support and information they need. Two practices have been supported by the screening programme to contact non responders by text message. The programme has not captured the outcomes of this intervention.</li> </ul>

• This relationship building can make the process more effective especially if information is transmitted in a timely way and there is a positive message about screening given by practice staff to women with questions

#### Challenges

- GP practices are under a lot of pressure with the pandemic response and breast screening may not be their top priority.
- It has been difficult to engage with GP practices without support from PCN cancer leads, and/or CRUK primary care leads to make the first introductions.

#### **Bowel Cancer Screening**

Bowel screening contacting eligible people via GP practices 2: People who have not participated in bowel screening in one GP practice received a text message (if mobile number available) or letter offering support.	Strengths:	Evaluation: Proportion of kits from non-responders completed
	<ul> <li>Text messaging is a known method to improve uptake in cervical screening programmes and may translate to bowel cancer screening.</li> <li>People with a positive FIT test have a significant risk of having /developing bowel cancer and understanding why people withdraw from the pathway after already completing screening is important.</li> </ul>	<b>Outcome</b> : Of 426 non responders 20 (4.7%) completed a kit after being contacted:
		<ul> <li>77 were aged 60 to 61, and 10 (14.1%) completed a kit after being contacted</li> </ul>
		<ul> <li>66 were aged 62 to 63,and 5 (9.9%) completed a kit after being contacted</li> </ul>
		• 79 were aged 64 to 66, and 2 (3.2%) completed a kit after being contacted
	Challenges	

- The screening coordinator cannot contact people directly so is dependent on practice staff
- GPs are under a lot of pressure with the pandemic response, and few are responding to screening coordinators offer of support
- 88 were aged 67 to 69, and 2 (2.7%) completed a kit after being contacted
- 116 were aged 70 to 75, and 1 (1.1%) completed a kit after being contacted

None of the completed test kits returned were abnormal.

#### Bowel screening contacting Strengths

eligible people through GP practices 3: Work with GPs in most deprived populations to contact non responders directly or via text message about participating and survey of views

- Contacting non responders directly often improves uptake and this is not something usually attempted in bowel screening
- GPs are part of PCNs who hold contracts specifying they must make efforts to improve participation in cancer screening programmes.

# **Evaluation:** Comparison of uptake of people from one practice invited for screening in 2019 (pre-pandemic) vs 2021, and understand reasons for non-participation

Outcome:

	Invited	Participation following routine invite (% uptake)	Participation after reminder
2019	136	70 (51.5%)	N/A
2021	247	155 (62.8%)	166 (67.2%)

#### Challenges

• As bowel screening coordinators are unable to contact non responders directly the intervention is dependent on the goodwill of GP practices who are currently under significant pressure with a backlog and seasonal vaccination initiatives.

Following reminder letters and survey sent to 92 non responders an additional 11 people equating to an increase in 4.4% completed a screening kit.

Reasons for non-attendance:

- A dislike of the bowel screening process.
- A fear of being diagnosed with cancer.
- I am healthy and feel fine, therefore I'm not currently worried about bowel cancer.
- Nobody in my family has ever had bowel cancer, therefore I feel I'm low risk.

Intervention	Strengths and challenges	Evaluation measure and outcome
Breast Cancer Screening		
Breast screening community engagement 1: Visit homeless shelter, talk to women, put up posters and leave leaflets	<ul> <li>Strengths:</li> <li>Engagement with a group who don't typically participate in screening</li> <li>Challenges:</li> <li>This is a group which is hard to engage with and who don't readily use health care services</li> </ul>	<ul> <li>Evaluation: Reflections of screening coordinator</li> <li>Outcome: <ul> <li>An informal conversational approach and leaving promotional material was considered better than a formal talk</li> <li>Raised awareness and provided ongoing opportunity to engage about breast health and any other issues</li> <li>Women reluctant to speak to screening coordinator during the visit</li> <li>Women reluctant to settle to hear information</li> </ul> </li> </ul>
Breast screening community engagement 2: Working with charities to identify groups and best approach to engaging with women (e.g., Women's Institute, BAME groups). Visiting vaccination centres, shopping centres, community centres with stand of leaflets and posters to engage public in conversation about screening.	<ul> <li>Strengths:</li> <li>Awareness raising in the community improves likelihood of people participating in screening</li> <li>Linking with organisations already involved with specific groups likely to be more successful at getting the message across</li> <li>Challenges:</li> </ul>	<b>Evaluation:</b> Reflections of screening coordinator <b>Outcome</b> : Breast screening coordinators have engaged with many individuals, groups and charities to assess how best to disseminate their message, this includes, working with a local charity Breast Mates and providing information for different groups.

#### Table 7: Community engagement interventions within the bowel and breast screening project

	<ul> <li>Difficult to assess whether effort and resource use into the intervention translates into significant change in uptake</li> </ul>	
Bowel Cancer Screening		
Bowel screening community engagement 3: Wider community engagement with press release to groups, leaflets, posters to places who engage with the 60-74 age group	<ul> <li>Strength:</li> <li>Awareness raising in the community improves likelihood people will participate in screening</li> <li>Challenges:</li> <li>Difficult to assess whether effort and</li> </ul>	<b>Evaluation:</b> Screening coordinator's reflections <b>Outcome:</b> Screening coordinators have visited high footfall areas to engage people in conversation about bowel screening with limited success. Some community groups have been keen to support improved visibility of bowel cancer screening as part of their work such as the Food Pantry in Liverpool.
	resource use into the intervention translates into significant change in uptake	
Bowel screening community engagement 4: Contacting community groups/charities supporting each of the main underserved groups each month (e.g., MIND, trans groups, religious groups, men's groups). Offer press release, tailored information to go on their social media sites plus hard copy of posters, and leaflets for centres.	<ul> <li>Strengths:</li> <li>Each underserved group will be the focus for a month e.g., men for the month of August, people from ethnically diverse groups in May and transgender people in April.</li> <li>Challenges:</li> <li>It may be difficult to make a measurable impact on the uptake of bowel screeping for</li> </ul>	<b>Evaluation:</b> Reflections of screening coordinator <b>Outcome:</b> The key messages conveyed varied slightly by each group that engaged with the screening coordinator – some groups opted for digital resources which were shared publicly via their website and/or social media. Others opted for physical resources only. We have a greater array of digital resources than physical resources, hence the slight variation in information.
	people in each of these groups from a single month of activity	The best resources available, that convey the BCSP message, are those focused specifically on screening. As such, future monthly community-focused campaigns will feature a more refined sample of resources, to

	<ul> <li>It will be difficult to measure any changes in uptake in these groups as uptake is not routinely or easily reported at this level</li> </ul>	<ul> <li>place focus on bowel cancer screening. The key messages conveyed will be:</li> <li>The dangers and risks that bowel cancer poses to health and lives – bowel cancer is second biggest cause of cancer deaths in the UK.</li> <li>What the screening process involves – what the FIT test involves, what process follows with normal and abnormal results?</li> <li>Where the FIT test can be carried out – "in the comfort and privacy of your own home"</li> <li>Who is eligible to participate in screening – everyone aged 60-74 and registered with a GP. Though you can request a test if you are older than 74.</li> <li>Few groups fed back their views of the materials but those who did said people found the information useful.</li> <li>The pandemic had a big impact on the likelihood of groups wanting to engage with screening coordinators with groups being more willing to disseminate information towards the end of lockdown.</li> </ul>
Breast cancer and Bowel Cancer Screen	ing	
Breast and bowel screening community engagement 1: Development of social media site to post relevant content supplied by screening services and comms teams	<ul> <li>Strengths:</li> <li>Having a range of different channels to disseminate the cancer screening message is likely to reach more people who use Facebook, Twitter and Instagram</li> </ul>	<ul><li>Evaluation: Response to posts on social media and numbers accessing sites</li><li>Outcome: It has been challenging for screening coordinators to get approval to set up social media pages for their screening programmes.</li></ul>
	Challenges	
	Setting up social media pages requires careful administration about the content	

going to people and the possible response which would need to be managed. This may be challenging within the NHS

#### Table 8: Administrative support activities

Intervention	Strengths and Challenges
Breast Cancer Screening	
Breast screening administration 1: Ensure contact details of people invited for screening are up to date so texts more likely to reach women	<ul> <li>Strengths</li> <li>Important to have up to date contact details for women to ensure text reminders are effective</li> </ul>
	<ul> <li>Ongoing process does not directly engage with people to improve participation in screening</li> </ul>
Breast screening administration 2: Covering for admin team when there were absences	<ul> <li>Strengths:</li> <li>Useful experience which may result in developing other interventions</li> <li>Improves routine day to day quality of service</li> <li>Challenges:</li> <li>Does not directly improve participation in screening</li> </ul>
Bowel Cancer Screening	
Bowel screening administration 3:	Strengths
Due to staff shortages screening coordinator supports the Specialist Screening Practitioner clinics by contacting GPs of positive patients for up-to-date information.	<ul> <li>Improves routine day to day quality of service</li> <li>Challenges</li> <li>Does not directly improve participation in screening</li> </ul>

Bowel screening administration 4 : Due to Strengths staff shortages screening coordinator supports SSP clinics by chasing overdue histology results.

• Improves routine day to day quality of service

Challenges

• Does not directly improve participation in screening

#### Direct engagement with those eligible for breast screening: reflections

Breast screening coordinators were able to engage directly with women invited for breast screening and those who did not attend their appointments. They had access to women's contact details via the National Breast Screening System and once lists of invited women were checked and updated by GPs, they sent out the invitations to women to call to make an appointment. Typically, when lists of women were downloaded and screening records opened for individual women due to be screened their contact phone numbers were not included. This meant screening coordinators needed to extract the information manually which was time consuming and could be prone to error. For women without mobile phones contact was via a landline phone call or letter rather than text message. Often women invited for the first time for screening did not have a phone number recorded on the NBSS system so could not be contacted.

Screening coordinators felt direct engagement with women through text messaging reminders was effective, if resource intensive, in prompting women to call the breast screening unit to make an appointment. Text messaging in bulk had to be limited to small batches so administrative staff were not inundated with calls over a short period of time.

Intervention 1 in Table 5 reports the response to text messaging and sending letter reminders to women. It is estimated that this response increases participation in screening by 5.9% (see case study 1). Of those 165 contacted after a routine invitation was sent, 71 (43%) responded to a text and a further 49 (30%) responded following the text and phone call. However, the estimated increase in participation of 5.9% is subject to a range of confounding factors so this estimate must be regarded with caution because:

- Women contacted may have been planning to contact the breast screening service but hadn't managed to before they received a text prompt and letter prompt
- Due to the pandemic a change to open appointments from fixed appointments, combined with the backlog of women due to be screened, meant that there were limited appointments available to offer women when they were reminded to call
- DNA rates for clinics didn't appear to change markedly despite the interventions (around 4%-5%)

For women who did not attend their appointment, attempting to contact them to re-book a time had limited success with a high proportion not answering the call. For interventions 2 and 4 reported in Table 5, between 82% and 86% of women who DNA'd were not successfully contacted. There were varied rates of re-booking appointments when screening coordinators did successfully contact women which ranged from 7% to 39% for interventions 2,3 and 4 in Table 5.

For women with double fixed appointments, reminding them to attend the appointment or calling prior to the invitation being sent to offer support and a convenient appointment time was thought to be helpful by screening coordinators but results from interventions 6, 7, and 8 in Table 5 do not show any consistent trend which could be attributed to the intervention.

From the outcomes of interventions employing direct contact with women eligible for breast screening, an approach involving texting and sending a letter to women as a reminder to book an appointment soon after a routine appointment is sent appears to result in a good response. Given the numbers of women invited for screening, the variation in uptake across breast screening programmes and the limited resource in the form of one whole time equivalent screening coordinator, it is likely to be more effective if the approach is:

• Targeted to practices with the lowest uptake e.g., the fifth of practices with the lowest uptake

 Implemented in conjunction with an IT solution to enable screening coordinators or administrators to electronically download contact details of women into their open screening episode

More work needs to be done to determine the most effective way of engaging women who do not attend for screening and those who have particular requirements as part of a double fixed appointment to support participation in breast screening programmes.

#### Screening coordination engagement with PCNs and GP practices: reflections

Two bowel cancer screening programmes engaged with Primary Care Networks and GP surgeries offering support to contact people who had not returned a bowel screening test kit during the previous 6 months to a year. One breast screening unit also engaged with PCNs to support them in contacting women who hadn't responded to a breast screening invitation and also spent some time building relationships with the practices to enhance communication between primary care, the screening programme and women invited for screening.

There are challenges to engaging with GP practices at this time. A combination of the impact of the pandemic and workforce shortages mean it is difficult for practices to engage in additional activities. However, each GP surgery belongs to a Primary Care Network of practices. Each PCN has a contract to provide Direct Enhanced Services (DES) to its population, and one element of the service specification around early cancer diagnosis is to improve local uptake of National Cancer Screening Programmes. Screening programmes worked with PCN coordinators and cancer leads to find practices with capacity and capability to work with non-responders.

The two bowel cancer screening programmes offering support to practices chose to target the fifth of practices in their catchment with the lowest uptake. Of those practices 2 agreed to work with the screening coordinators.

Supported by one bowel cancer screening programme (Table 6, intervention 2) a GP practice texted 426 non responders about participating in the screening programme and 20 (4.7%) subsequently completed a kit. Importantly half of those who responded were aged 60 to 61 and had received their first ever invitation to be screened in the previous year and hadn't, at that time, taken up the offer of screening. At the time of the reminders (February 2022) there was a BBC Radio 5 live podcast by Dame Debra James aged 40 who described her bowel cancer treatment and re-iterated her message to people to 'check your poo' which was widely reported in the rest of the mainstream media and raised awareness nationally of the condition.

A second practice supported by a bowel cancer screening programme also sent out text messages to all non-responders in 2021 (Table 6, intervention 3). Compared to 2019 there was an 11% increase in participation in 2021 from the routine offer of screening. Following a reminder being sent to 92 non responders 11 (4.4%) completed a screening kit, bringing the total proportion of those participating to 67.2% of those invited in 2021.

The 2 GP practices supported by the breast screening programme to send out text messages did not record the outcomes of the intervention. However, it was part of a relationship building exercise with practices and may well be a reasonably straightforward intervention to put in place.

The main barrier to this approach for both bowel and breast cancer screening was the reluctance of GP practices to take up the offer of support to contact non responders during the pandemic due to capacity and infection control issues of inviting patients in. However, this intervention may be feasible if PCNs with practices with the lowest uptake could employ screening coordinators covering both bowel and breast cancer screening. They would be the main point of contact with the relevant breast and bowel screening programmes.

#### Breast and bowel screening coordinators and community engagement: reflections

A range of community engagement activities were carried out by both the breast and bowel screening programmes. These ranged from organising breast screening events with large local employers (eg Astra Zeneca), setting up stands in areas of the community with a higher footfall, contacting community groups to ask them to disseminate materials and visiting specific groups such as hostels to give talks. All these activities aimed to increase the visibility of the screening programmes in the community, with some targeting underserved groups. It wasn't possible to evaluate this activity in terms of its possible impact on breast and bowel screening participation. However, it is always important to continually offer information, education and support in the community to raise awareness of cancer.

The media and social media are also important routes to disseminate information. Although not implemented in the Cheshire and Merseyside, other programmes support media interviews of local people who have been found to have cancer via their screening programmes and have recovered. In addition there have been high profile instances when celebrities such as Jade Goody who had cervical cancer and Dame Debra James with bowel cancer have made an impact on people attending for screening.

The breast and bowel screening programmes did attempt to put in place social media routes to information for the Cheshire and Merseyside population, noting similar initiatives in neighbouring areas. However, the barriers to the programmes having their own Facebook page (such as exist for GP practices to disseminate information) have been very difficult to overcome and a source of great frustration to the screening coordinators. It was not clear why it was so difficult for Trusts to agree to a social media presence for the screening programmes as this would be an important channel to promote the programmes, provide information and signpost people to further resources.

#### Key question 3: What would be the cost of adopting the solution at scale?

Data on local costs was requested from the programme. This amounted to the funds received by each Trust to employ an Administrative and Clerical (A&C) band 4 screening coordinator including on costs. Trusts received a maximum of £60,414 which covered the funding of a screening coordinator for 2 years from the beginning of October 2020 to the end of September 2022. No screening coordinator was in post for the full 2 year period and screening coordinators undertook a range of different interventions whilst they were in post. In order to assess the costs of screening coordinators versus the benefit in increased uptake, estimates were made based on interventions where an increase in people participating in screening was reported.

Two interventions (case study 1 and 7) showed a demonstrable change in uptake due to the activities of the screening coordinator. These were:

- Increase in participation by women invited to book an appointment for breast screening who hadn't responded ≥ 2 weeks following routine invitation. A text message was sent at 2 weeks and telephone call /letter after a further week (estimated 5.9% increase in participation)
- Increase in participation by people contacted by the GP practice who had not taken up the offer of bowel cancer screening when offered in the previous year (estimated 4.4% increase in participation)

#### Breast screening costs and activity

Based on the numbers of people invited for screening in 2019/20 (see Table 2) and the uptake pre-pandemic the additional numbers of women per year screened and referred for assessment with an increase of 5.9% can be estimated. If screening coordinators in post were able to contact
all women who didn't make an appointment to be screened and improved participation by 5.9% the overall uptake for Cheshire and Merseyside breast screening units would be between 64.1% and 75.8% (Table 9). An additional 310 women will be referred for assessment by breast screening units in Cheshire and Merseyside. Nationally in 2020/21 around 9 women per 1000 screened were diagnosed with breast cancer<sup>2</sup>. It's estimated that an additional 8,308 women would be screened if uptake increased by 5.9% resulting in an estimated 24 women diagnosed with breast cancer.

Five screening coordinators were employed, one for each screening programme at a cost of £30,207 per year including on costs. This doesn't include costs of other people involved in supporting the screening coordinator in their role or the cost of the intervention (text messaging, phone calls, and letters). It is unclear how many screening coordinators would be needed full time to be able to implement this intervention across Cheshire and Merseyside, but they would need to contact in the region of 35,000 people by text, phone, or letter to achieve the estimated increased participation. If screening coordinators focussed on the fifth of practices with the lowest uptake this may be more manageable, with around 7,000 women needing to be contacted per year. With only a fifth of people being reminded to take part in screening the increase in the number of women referred for diagnostic assessment would be around 62 cases rather than 310 per year. With around 1661 additional women screened per year this would result in around 14 additional women diagnosed with breast cancer per year.

Overall, with an estimated investment of around £150,000 per year on screening coordinators (1 for each screening programme) focussed on this one intervention for one fifth of the eligible women, this equates to £2419 per woman referred and £7142 per woman diagnosed with breast cancer.

Breast screening unit number invited and % potential uplift	Estimated women Screened (uptake %)	Estimated additional women screened per year	Estimated referrals for Assessment per year(%)	Estimated additional women referred per year
Crewe 15,454 invited	10,816 (69.9%)*	N/A	398 (3.7%)*	N/A
5.9% uplift	11,714 (75.8%)	898	433	35
East Cheshire & Stockport 25,029 invited	17,090 (68.3%)	N/A	758 (4.4%)*	N/A
5.9% uplift	18,572 (74.2%)	1481	817	59
Liverpool 47,485 invited	30,454(64.1%)*	N/A	1072 (3.5%)*	N/A
5.9% uplift	33,239 (70.0%)	2785	1163	91
Warrington Halton, St Helens and Knowsley 25,573 invited	19,248 (75.3%)*	N/A	707 (3.7%)*	N/A
5.9% uplift	20,765 (81.2%)	1517	768	61
Wirral & Chester 27,591 invited	20,087 (72.8%)*	N/A	761 (3.8%)*	N/A
5.9% uplift	21,714 (78.7%)	1627	825	64
Cheshire and Merseyside	97,695(69.2%)	N/A	3696	N/A

# Table 9 Estimated number of women screened and referred for assessment treatment if text, phone, and letter reminders for those offered screening with an increased participation 5.9%

<sup>2</sup> https://digital.nhs.uk/data-and-information/publications/statistical/breast-screening-programme/england---2020-21/mainreport6#section-6-cancers-detected

141,132				
5.9% uplift	106,004(75.1%)	8,308	4006	310
Cheshire and Merseyside most deprived 20% targeted and 5.9% uplift	7,026	1661	801	62
*Figures from NHS breast screening programme 2019-20 https://digital.nhs.uk/data-and-				

information/publications/statistical/breast-screening-programme/england---2019-20

#### Bowel cancer screening costs and activity

Based on the numbers of people invited for bowel screening in 2019/20 (see Table 1) and the uptake pre-pandemic, the additional numbers of people per year screened and referred for assessment with an increase of 4.4% can be estimated. If screening coordinators in post were able to contact all people who didn't make an appointment to be screened and improved participation by 4.4% the overall uptake for Cheshire and Merseyside breast screening units would be between 62.9% and 68.6% (Table 10). An additional 183 people will be referred to bowel screening units for assessment in Cheshire and Merseyside.

Nationally around 1 in 75 people screened will have colorectal cancer, or cancer prevented by removing the cancerous polyp during the screening colonoscopy and 1 in 23 will have an advanced adenoma detected<sup>3</sup>. screening coordinators based in GP practices were able to contact people who didn't complete a screening kit and improved participation by 4.4% the overall uptake for Cheshire and Merseyside bowel cancer screening units would be between 63.2% and 68.9% (Table 10). An additional 9,198 people would participate in screening resulting in around 183 people being referred for diagnostic assessment. If all 183 people were adequately assessed, it is likely that around 15 people would be diagnosed with colorectal cancer or have a cancer removed during the screening colonoscopy and 48 people would be diagnosed with an advanced adenoma.

Three screening coordinators were employed, one for each screening programme at a cost of £30,207 per year including on costs. This doesn't include costs of other people involved in supporting the screening coordinator in their role or the cost of the intervention (text messaging, phone calls, and letters). It is unclear how many screening coordinators would be needed full time to be able to implement this intervention across Cheshire and Merseyside, but they would need to contact in the region of 80,000 people by text, phone or letter to achieve the estimated increased participation. If screening coordinators focussed on the fifth of practices with the lowest uptake this may be more manageable, with 14,500 non responders to contact per year. With only a fifth of people being reminded to take part in screening the increase in the number of people referred for screening colonoscopy would be around 37 cases rather than 183 per year. This would result in 3 people diagnosed with colorectal cancer or have a cancer removed during the screening colonoscopy and around 10 people would be diagnosed with an advanced adenoma.

Overall, with an estimated investment of around £100,000 per year on screening coordinators focussed on this one intervention (1 screening coordinator per programme) targeted at a fifth of the population it would cost around £2,707 per person referred for assessment and £33,300 per person diagnosed.

<sup>3</sup> Li, S.J., Seedher, T., Sharples, L.D. *et al.* Impact of changes to the interscreening interval and faecal immunochemical test threshold in the national bowel cancer screening programme in England: results from the FIT pilot study. *Br J Cancer* (2022). https://doi.org/10.1038/s41416-022-01919-y

# Table 10: Estimated number of people screened and referred for bowel cancer screeningassessment if text, phone, and letter reminders for those offered screening with anincreased participation 4.4%

Bowel screening unit	Estimated people Screened (uptake %)	Estimated additional people screened per year	Estimated number referred for assessment (2%) <sup>1</sup>	Estimated Additional people referred per year
Cheshire 67,330 invited	43,207(64.2%)*	N/A	864	N/A
4.4% uplift	46,188(68.6%)	2,981	923	59
Liverpool and Wirral 59,634 invited	34,904 (58.5%*)	N/A	698	N/A
4.4% uplift	37,509(62.9%)	2605	750	52
Merseyside and North Cheshire 82,772 invited	50,272 (60.7%)*	N/A	1005	N/A
4.4% uplift	53,884(65.1%)	3612	1077	72
Cheshire and Merseyside 209,736	128,383(61.2%)	N/A	2567	N/A
4.4% uplift	137,581(65.6%)	9,198	2750	183
Cheshire and Merseyside most deprived 20% targeted and 4.4% uplift 41,947	27,516	1,839	550	37

\*Figures from NHS Screening Programmes: KPI reports 2019 to 2020; https://www.gov.uk/government/publications/nhs-screening-programmes-kpi-reports-2019-to-2020

#### Caution with scaling up implementation of interventions using these estimates

The estimates of the numbers of additional people screened across Cheshire and Merseyside with the implementation of these particular breast screening and bowel screening interventions have considerable limitations. The estimates are based on small sample sizes from 3 or 4 specific GP practices and clinics and although the results illustrate the proof of concept that these interventions are promising, they are not robust enough in their set up, execution and reporting to be used as the basis for scaling up this approach. Factors which will affect these estimates include:

- Adequate engagement from all GP practices
- Sign up to the implementation of these specific interventions by screening programmes
- Funding of an adequate number of screening coordinators and admin support staff
- Development of a standard process (operating procedure) for contacting people who are either due to be screened or who have not participated in screening following an invitation including but not limited to:
  - IT solutions to access peoples contact details in an efficient way (however this is a barrier to all national bowel screening programmes)
  - o IT solutions to efficiently contact people via text, phone and letter
  - $\circ \quad \text{Time of day of contact} \\$
  - Content of the message via each channel

- Tailoring the method of contact/content of the message for different underserved population groups
- Plan of numbers of people contacted via bulk text messaging or letters to avoid inundating staff with calls requesting appointments/test kits

If there is further interest in implementing these interventions it is recommended that a pilot, project planned specifically for this approach, is developed. This would enable a standard approach to implementation, reporting and follow up of patients. Patients referred for assessment with a positive test result who are diagnosed with bowel or breast cancer can be tracked and evaluated for cancer stage and compared with those diagnosed via the symptomatic route. Early-stage cancer is more likely to be diagnosed in people who are screened compared to those diagnosed via the symptomatic route when a late stage cancer diagnosis is more probable. Increased costs in treating and managing late stage cancer diagnosis compared to early stage disease means these interventions may not only deliver sustainable increases in screening participation but reduced secondary care costs over the longer term. A focus on GP practices with the lowest uptake and highest levels of deprivation will also be important to maximise the effectiveness of this approach to make most efficient use of the screening coordinator resource whilst addressing inequalities in screening uptake.

### 4. Intervention 2: Cervical Screening Text Message Reminders

The approach aimed to target all patients due to attend for cervical screening using text message reminder technology.

#### Literature review: Cervical screening text messaging

The search for published evidence identified three relevant studies on the effectiveness of text messaging to improve the uptake of cervical cancer screening. Two further studies were identified by a search for grey literature. These studies included three UK studies, all of which were conducted in London: one randomised controlled trial (RCT) (Huff et al 2017), a service evaluation (Ryan et al 2019) and unpublished results from a London pilot study. The other studies identified were from a Portuguese RCT about the effectiveness and cost effectiveness of a text message intervention (Firmino-Machado et al 2019a; 2019b).

In two UK studies, uptake increased by approximately 4% to 5% following either a simple reminder or a GP endorsed text message. However, in the UK RCT, other forms of text message content e.g. social norm or gain/loss framed messages did not result in a statistically significant increase in uptake compared to the "no text message" counterfactual.

In the third UK study, between 5% and 13% of women in different age groups booked an appointment for screening following a text reminder message, however the proportion of women who attended the appointment is unknown.

In the Portuguese RCT, uptake improved by approximately 11.3% compared to a written invitation letter alone, however this study included follow-up text messages and automated phone calls to women who did not respond to the initial text message.

Limited details were available for many of these studies and they varied considerably in sample size and the exact nature of the text message intervention. All three of the UK studies were conducted in London. There is some evidence that text messaging may be most effective in younger age groups.

#### Modelling trajectories: Cervical screening text messaging

The intention of the text messaging reminder invitation is to increase coverage and uptake of cervical cancer screening by eligible women. The proposed model being implemented in Cheshire and Merseyside is similar to that previously implemented in London across all CCGs

between September 2018 and March 2019<sup>4</sup>. London reported increases of 4.8% overall and 5.9% in the 50 to 64 age group. We have applied these percentages to the percentage coverage achieved in Cheshire and Merseyside in both age groups as a way of estimating the potential impact of the text messaging initiative (Table 9).

Coverage is the number of eligible women who have been adequately screened over the previous 3.5 years for those aged 25 to 49 (as they are invited for screening every 3 years) and 5.5 years for those aged 50 to 64 (as they are invited for screening every 5 years), so in order to estimate the additional number of women likely to be screened in a year we divided the calculated number of additional women either by 3.5 or 5.5.

In table 9 we have also estimated referrals to colposcopy resulting from increased coverage due to text messaging reminders. National data suggests that 4.2% of women receiving primary HPV screening will be referred to colposcopy (Rebolj et al 2019). This compares to 3.9% for women receiving liquid cytology-based screening. Based on the most recent data available from PHE health profiles coverage statistics for 2019/20, if there was an increase in screening coverage by 4.8% then an estimated additional 7829 women are likely to be screened across the Cheshire and Merseyside CCGs per year. If the increase in coverage was higher at 5.9% the additional number of women likely to be screened yearly would be 9623. It is estimated that the additional women being screened will generate an additional 264 to 405 immediate referrals to colposcopy clinics in Cheshire and Merseyside per year.

	Women age 25-49	Women age 50-64	Total women
Number of women screened per year	87,105	32,474	119,579
Number of women invited for screening	119,510	43,602	163,112
Coverage for 2019/2020	72.9%	74.4%%	73.3%
Coverage uplifted by 4.8%	77.7%	79.2%	78.1%
Coverage uplifted by 5.9%	78.8%	80.3%	79.2%
Total number of women screened (with 4.8% uplift)	92,841	34,567	127,408
Additional number of women screened (4.8% uplift)	5736	2093	7829
Total number of women screened (5.9% uplift)	94,156	35,046	129,202
Additional number of women screened (5.9% uplift)	7051	2572	9623
Total estimated Colposcopy referrals	3658	1364	5022
Total estimated Colposcopy referrals (4.8% uplift)	3834	1452	5286
Additional colposcopy referrals (4.8% uplift)	176	88	264
Total estimated Colposcopy referrals (5.9% uplift)	3955	1472	5427
Additional colposcopy referrals (5.9% uplift)	297	108	405

# Table 9: Cheshire and Merseyside summary of estimated additional women screened as a result of use of text messaging reminders per year based on 2019/2020 figures\*

\*Figures from PHE Fingertips 2019/20 available at

https://fingertips.phe.org.uk/search/cervical%20screening#page/9/gid/1/pat/166/par/E38000174/ati/7/are/P88002/iid/93726/age/273/s ex/2/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1/page-options/car-do-0 and https://fingertips.phe.org.uk/search/cervical%20screening#page/9/gid/1/pat/166/par/E38000174/ati/7/are/P88002/iid/93725/age/299/s ex/2/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1/page-options/car-do-0

Other factors will have an impact on the number of women screened, the number of samples sent to the laboratory and the number of women referred to colposcopy (Rebolj et al 2019)<sup>5</sup>.

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<sup>4</sup> Digital Text Messaging London Pilot Presentation on Lon

<sup>5</sup> Rebolj M, Rimmer J,Denton K, Tidy J, Mathews C et al Primary cervical screening with high risk human papillomavirus testing: observational study BMJ 2019; 364:l240364 doi: https://doi.org/10.1136/bmj.l240

These include:

- Around 12.7% of women who are routinely screened are put on early recall for a test at 12 or 24 months.
- Of those women who are recalled early a proportion will be referred for colposcopy. These additional referrals are not included in the 4.2% of women who are immediately referred following routine screening.

A small proportion of women who are screened will need a repeat test within 3 months, as the sample, for a range of reasons, is not adequate for testing. It is not yet clear exactly what proportion this will be with the new HPV primary testing protocol in place.

Modelling figures for Cheshire and Merseyside CCGs and by GP practice are available on request.

#### Evaluation support for the cervical screening text messaging project

Work to implement the text messaging project has been ongoing since late 2019 and plans were continuing up to March 2022 despite the official pause due to the ongoing COVID-19 pandemic. At this point the challenges to implementation became insurmountable with the inevitable decision not to go ahead with the intervention. The challenges to implementation initially concerned the pandemic and the capability and capacity of Primary Care to put the intervention in place. Later in the planning process gaining approval for the use and flow of cervical screening data between the NHS, the text messaging service and the Local Authority commissioning the project was problematic. The solution to novate the contract to NHSEI North West region was proposed as this would ensure that data remained in the NHS. However, this was rejected by NHSEI.

During the period January 2020 to March 2022 evaluation support was provided to develop the evaluation plan and logic model, review and advise on data collection, and timing of data submission for analysis and review documentation from previous similar projects.

#### Key question 1. How has the cervical screening project been implemented?

The cervical screening text messaging project was not implemented so this question cannot be addressed.

# Key question 2. How has uptake of cervical cancer screening changed as a result of the text messaging intervention for participating GP practices?

The cervical screening text messaging project was not implemented so this question cannot be addressed.

#### Key question 3. What would be the cost of adopting the solution at scale?

The cervical screening text messaging project was not implemented so this question cannot be addressed.

### 5. Intervention 3: Community Engagement

The aim of this project was to support community organisations to influence screening uptake and coverage through:

- Development of an education and training package for frontline community workers
- Provision of funding to local authority/ Clinical Commissioning Group areas to engage community organisations in screening promotion

#### Literature review: Community engagement

The search for published evidence identified relevant studies on the effectiveness of using community engagement to improve the uptake of population screening. No additional studies were found by a search for grey literature.

These studies were all conducted in the US and reported an intervention consisting of training for lay health workers followed by the delivery of an educational programme for local communities. Nguyen et al (2010) targeted Chinese Americans and focused on bowel cancer screening. Rodriguez et al (2019) targeted African Americans and focused on breast and cervical cancer. Berger et al (2017) targeted Chinese and Vietnamese Americans and focused on breast screening.

The WHO definition of lay health workers is "those who live in a community, are selected by and accountable to it and work after receiving a short, defined training" Nguyen et al (2010).

Nguyen et al (2010) and Rodriguez et al (2019) demonstrated an improvement in knowledge following educational sessions. Some information was available on screening uptake, with Nguyen et al (2010) reporting a 56% increase in FOBT screening five to six months later and Rodriguez et al (2019) reporting a 33% increase in screening uptake for breast or cervical cancer amongst a sample of women who received the educational programme and were followed-up two months later. Berger et al (2017) showed limited improvements of knowledge which may have been due to a high level of baseline knowledge and high past screening attendance amongst workshop attendees.

No UK studies were identified. The applicability of the study populations to the UK is uncertain. Limited information was available on screening uptake following intervention and the available information was self-reported.

The studies all had small sample sizes and varied in the nature of the training received by lay health workers. None of the studies used online training. The educational programmes delivered to participants were similar in that they were adapted versions of national curricula.

#### Evaluation support for the community engagement project

In January 2020 plans to implement the community engagement project were being developed. This involved developing an online training package to increase cancer screening awareness and setting up a process for local authorities to submit proposals about how they might develop community engagement activities to raise awareness about cancer screening locally with the aim of improving uptake and coverage. This could be through employing someone to carry out the role or funding local community organisations who were practised in this type of engagement. Evaluation support at this early stage of the initiative involved recommending the types of data items collected which would facilitate evaluation during and at the end of the project. Commenting on documentation going out to local authorities from an evaluation perspective was also important.

With the first lockdown in March 2020, it became clear that the community engagement activities element of this project would be severely delayed as Local Authority Public Health teams were focussed on the COVID-19 pandemic and there was no spare capacity, in addition face to face community engagement was not permitted in the context of the pandemic. By early 2021 it was clear the community engagement activities would not be implemented in the near future and funding was returned to The Cheshire and Merseyside Cancer Alliance . The development of the online digital toolkit was severely delayed but is about to be launched (November2022).

Key Question 1. How was the community engagement project implemented?

The community engagement project has not yet been implemented so this question cannot currently be addressed.

Key Question 2. Did the community engagement events improve cancer screening awareness and intention to be screened in those engaging with the events?

The community engagement project has not yet been implemented so this question cannot currently be addressed.

Key Question 3. What would be the cost of implementing community engagement at scale?

The community engagement project has not yet been implemented so this question cannot currently be addressed.

# Appendix 1: Cancer screening programmes and clinical Commissioning groups

The Breast and Bowel Cancer Screening Project Implementation Document circulated at the outset of the project specified the following breast and bowel screening programmes would be funded to employ screening coordinators to improve uptake.

Breast screening programmes:

- East Cheshire and Stockport Breast Screening Programme
- Warrington, Halton, St Helens and Knowsley Breast Screening Programme
- Liverpool, Sefton and Knowsley Breast Screening Programme
- Wirral and Chester Breast Screening Programme

Bowel screening programmes:

- Merseyside and North Cheshire Bowel Cancer Screening Programme
- Liverpool and Wirral Bowel Cancer Screening Programme
- Cheshire Bowel Cancer Screening Programme

The Cervical Cancer Screening Project Initiation Document circulated at the outset of the project specified that GPs within the following CCGs would be asked to participate in the project so reminder text messages could be sent to women registered with them who had been invited for cervical screening:

Clinical Commissioning Groups:

- NHS Halton CCG
- NHS Knowsley CCG
- NHS Liverpool CCG
- NHS South Sefton CCG
- NHS Southport and Formby CCG
- NHS St Helens CCG
- NHS Warrington CCG
- NHS Cheshire CCG

# Appendix 2: Evaluation plan and methodology

An evaluation plan outlining the evaluation logic model, questions and methodology was developed during January to April 2020. This coincided with the start of the COVID-19 pandemic when all cancer screening programmes were paused for three months from March 2020. In response the evaluation methodology for each of the three initiatives was modified to take into account delayed start dates and the uncertainty about how and what interventions would actually be implemented.

#### **Evidence review**

As part of the initial scoping work for the evaluation a literature review of published and unpublished literature related to the chosen interventions was carried out. The interventions to be implemented by the programme across Cheshire and Merseyside were selected on the basis of similar interventions that had been successful in other parts of England. The evidence review searched for literature relevant to the following three questions:

- 1. What is the effectiveness of using text messaging to improve participation in the cervical cancer screening programme?
- 2. What is the effectiveness of using screening co-ordinators to improve participation in the breast and bowel cancer screening programmes?
- 3. What is the effectiveness of using community engagement to improve participation in population screening in underserved populations?

Searches of three databases (Medline, Embase and Cochrane Library) were conducted on 17<sup>th</sup> February 2020 for studies from the previous ten years.

Targeted internet searches for grey literature were conducted, including searches of NICE Evidence and the TRIPdatabase (February 2020) and Google searches (March 2020). The evaluation team applied a pre-specified rule for when to stop screening the results of Google searches (i.e. the first 50 results) and also accepted any grey literature reports relating to known relevant projects supplied by the project team.

The results of the evidence review are summarised in the findings and are set out in Appendix 3.

#### Modelling potential impact on services

Based on the most recent figures about pre-pandemic cancer screening uptake in 2019/20 a range of trajectories were developed to model the impact on breast and bowel screening services of improved participation of 2%, 4% and 6%. Trajectories based on 4.8% and 5.9% were used for the cervical screening initiative based on the outcomes of recent pilot studies in London using a similar approach. The improvement trajectories show the impact that each intervention might have on the number of people being screened and also estimate the likely referrals to screening assessment services. Baseline data of screening uptake was extracted from:

- Bowel screening uptake for the year 2019/20 published by Public Health England (PHE) in March 2021, defined as the proportion of men and women aged 60 to 74 invited to participate and who are adequately screened
- Breast screening uptake data returns published by NHS Digital for 2019/20, defined as the proportion of eligible women aged 50 to 70 invited who attend for screening and were adequately screened within 6 months of receiving their invitation
- Cervical screening coverage for 2019/20 published by PHE in March 2021, defined as the proportion of women eligible for screening aged 25 to 49 who were adequately screened in the last 3.5 years and for those aged 50 to 64 adequately screened in the last 5.5 years.

The results of the modelling for Cheshire and Merseyside is summarised in the findings section.

#### Breast and bowel screening coordinators project

The aim of this project was to increase breast and bowel screening participation by the recruitment of screening coordinators by NHS provider trusts, who would hold structured conversations and other interventions with people who are about to be screened or who have not responded to the offer of screening.

# Evaluation questions and the logic model: Breast and bowel screening coordinators project

During the early phase of the project the evaluation questions and logic model were developed. The key questions for the breast and bowel screening project are:

- 1. How has the screening coordinator initiative been implemented?
- 2. Is the screening coordinator initiative on track to achieve the goal of improving participation in the screening programmes particularly in underserved groups?
- 3. What would be the cost of adopting the solution at scale?

In order to answer these questions a logic model was developed and evolved as the screening coordinators agreed on the specific interventions.

#### Figure 1: Breast and bowel cancer screening coordinator project logic model



For the breast and bowel screening coordinator interventions, tailored evaluation approaches were developed by SPH depending on the type of intervention the screening coordinators decided to implement. Data collection was carried out by the screening coordinators with support from SPH. Methods included collecting data on the number of people who booked screening appointments following text message reminders and asking people whether they intended to be screened or what was difficult in participating in screening. The evaluation approach for each intervention is outlined in the findings section.

The evaluation team carried out interviews and had meetings with each of the screening coordinators regularly to assess the implementation of interventions, and develop evaluation approaches the screening coordinators could easily use to collect data.

Routinely published national data was used as part of the evaluation including:

- Uptake of bowel and breast cancer screening at GP practice and screening unit level across Cheshire and Merseyside
- Most recent Index of Multiple Deprivation for all GP practices in Cheshire and Merseyside

#### Data analysis: Breast and bowel screening coordinators project

For qualitative information collected by screening coordinators from people eligible for screening a thematic semantic approach was used to organise the emerging themes.

For quantitative data collected for specific local interventions the data was analysed and descriptive statistics used to show changes in uptake within particular cohorts of people invited for screening. Changes in uptake and coverage of bowel and breast cancer screening are compared against the improvement trajectories developed in the design phase of the evaluation as a test of whether the local results are the same as might have been expected from the modelling.

#### Cervical screening text messaging project

The aim of this project was to increase cervical screening participation across Cheshire and Merseyside by implementation of a text messaging reminder service through GP practices. The combined impact of the pandemic and navigating complex governance and contractual issues led to delays in implementation and subsequently to the decision not to mobilise the intervention across Cheshire and Merseyside at this time. However preparatory evaluation activities were undertaken and are described below.

#### Evaluation questions and the logic model: Cervical screening text messaging project

During the early phase of the project the evaluation questions and logic model were developed. The key questions for the cervical screening project are:

- 1. How has the cervical screening project been implemented?
- 2. How has the coverage of cervical cancer screening changed as a result of the text messaging intervention for participating GP practices?
- 3. What would be the cost of adopting the solution at scale?

In order to answer these questions a logic model was developed and evolved as the intervention was designed for implementation by the project.

#### Figure 2: Cervical cancer screening text message reminder project model



Resources used	Things done	What will be achieved by the activities	Effects of activities	Impact of activities
Funding of project Project Manager	Procure and agree contract with iPlato Agree contract with the NHS Cervical	People and their contact details correctly identified	People participate in screening	Improved early detection of pre- cancerous conditions and
iPlato text messaging provider	Screening Administration Service Agree data items	People contacted either with a conversation, text message or both		cervical cancer in those participating in screening
NHS Cervical Screening Administration Service	Recruit GP practices to the project Agree start date with all, stakeholders	Data collated about the success in contacting people using text messaging		morbidity and mortality as a result of early detection and treatment of pre- cancerous conditions and cervical cancer
	Run text messaging intervention			

#### Evaluation approach: Cervical screening text messaging project

The evaluation plan for the text messaging intervention included the analysis of the uptake of cervical screening before and during the text messaging project by GP practices. Qualitative interviews of people within the cervical screening service such as the cytology laboratory manager, staff from practices involved in administering the cervical screening and colposcopy leads who would see increased referrals were planned.

#### Data collection and analysis: Cervical screening text messaging project

As part of the intervention to send text messages to women invited for cervical screening a range of data items were requested from the NHS Cervical Screening Administration Service who worked with the text message provider to deliver the intervention. This includes data requested at GP level with the data items disaggregated by text received and text not sent/not received:

- Eligible women invited
  - Number and % of women aged 25-64 invited within the quarter
  - Number and % of women aged 25-49 invited within the quarter
  - Number and % of women aged 50-64 invited within the quarter
- Age Uptake at 18 weeks (received text vs. did not receive text)
  - Number and % of women aged 25-64 screened within the quarter
  - Number and % of women aged 25-49 screened within the quarter
  - Number and % of women aged 50-64 screened within the quarter
- Deprivation Uptake at 18 weeks (received text vs. did not receive text)
  - IMD decile/quintile
- Time to screening Days between invitation and screening (received text vs. did not receive text)
  - o IMD decile/quintile

Routinely published national data were downloaded as part of the evaluation including:

- Coverage of cervical screening at GP practice and CCG level across Cheshire and Merseyside
- Most recent Index of Multiple Deprivation for all GP practices in Cheshire and Merseyside

For the cervical screening text messaging project, the planned analysis included:

- Analysis of the text messaging activity such as the number of women sent text messaging reminders, the number of bounce-backs and wrong numbers, the number of women opting out of receiving further text message reminders
- Analysis of locally provided data on the number of women eligible, invited, booking and attending a cervical cancer screening appointment for those GP practices participating in the project. This would allow the evaluation team to monitor cervical cancer screening uptake and coverage at only those practices within a CCG participating in the project
- Analysis of national cervical screening uptake and coverage data to assess the impact of the project on uptake and coverage at CCG level
- Analysis of cytology laboratory activity to measure any changes as a result of the project.
- Analysis of colposcopy activity to measure any changes as a result of the project
- Analysis of the cost data provided by the project.

The planned data analysis is at GP practice level so that any GP practices not participating in the project are excluded from the analysis. GP practice level deprivation scores are planned to be used to assess the extent to which the project impacted on existing screening inequalities, as deprivation is a helpful proxy for underserved populations.

Comparisons of quantitative data were to include:

- Trends in uptake and coverage of cervical cancer screening by GP practice before and after the text messaging project, analysed to show any differences in the trends since the start of the text messaging project. As a counterfactual this would need to be reviewed in the light of the impact of the COVID-19 disruption on cervical screening uptake.
- Changes in uptake and coverage of cervical cancer screening were to be compared against the improvement trajectories developed in the design phase of the evaluation as a test of whether the local results are the same as might have been expected based on the literature.

For the qualitative information, the planned evaluation approach was a thematic semantic analysis of the responses to the semi structured interviews and surveys to organise emerging themes and understand the perception, opinions and experiences of those involved in cervical screening.

#### Community engagement project

In order to support community organisations to raise awareness of cancer screening in the population the project planned to develop an education and training digital toolkit for frontline community workers and to provide funding to local authorities to engage community organisations in screening promotion activities. It was planned that the evaluation would focus on the impact of the intervention on cancer screening awareness and intention to participate in cancer screening programmes when invited. The online digital cancer screening toolkit is about to be launched (November 2022) however the community engagement activity element of this workstream was not implemented due to the COVID -19 pandemic, however preparatory evaluation activities were undertaken.

#### Evaluation questions and the logic model: Community engagement project

During the early phase of the project the evaluation questions and logic model were developed. The key questions for the community engagement project are:

- 1. How was the community engagement project implemented?
- 2. Did the community engagement events improve cancer screening awareness and intention to be screened in those engaging with the events?
- 3. What would be the cost of implementing community engagement at scale?

Figure 3:Community engagement project logic model



#### Evaluation approach: Community engagement project

The planned approach to the evaluation was largely focussed on understanding the implementation and utilisation of the training programme with a combination of semi structured interviews, surveys of participants and data about website usage.

For community events the SPH team worked with organisers to ensure methods to assess change in cancer screening awareness and intention to participate in screening are incorporated as part of the events in addition to the capture of demographic information about participants.

#### Data collection: Community engagement project

This initiative was about supporting community organisations to influence screening uptake and coverage by developing an on-line education and training package for frontline community workers to become patient navigators with the intention of providing funding to local authorities to engage community organisations in screening promotion activities. In order to evaluate this intervention, the SPH team interviewed and surveyed stakeholders involved in the planning, set up and implementation of the training and set up of the intervention. In addition a range of data items about the activities undertaken were requested. These included:

- date when online toolkit is launched
- number of people accessing online toolkit
- Local authority (LA) funding and implementation plan
- number and type of organisations taking part in project receiving funding via the LA
- number of community workers trained by community organisation and LA
- number of LAs who were not able to fully implement their plans
- the number of screening promotion activities that took place by LA
- for each activity/event:
  - o venue/setting where the event/activity took place

- type of activity e.g. standalone workshop, session run within a broader community activity, stall at a health and wellbeing fair
- o which community worker(s) were involved in delivering the event/activity
- description of type of group or community taking part
- o date event/activity took place
- o number of people attending/taking part
- pre and post event/activity cancer screening awareness survey results
- o activity/event costs
- information on the total costs of setting up and running the community engagement cancer screening project

This was the original evaluation plan for the project but as one element of the workstream (cervical project) was delayed due to governance and contractual issues previously mentioned, so therefore not implemented all of this plan has not been executed.

#### Data analysis: Community engagement project

For the community engagement cancer screening project, the planned analysis of quantitative data included:

- Analysis of the effectiveness of engagement with community organisations including the number and type of community organisations participating, the number of community workers receiving training, dropout rates for community organisations and community workers
- Analysis of the number and type of screening promotion activities and where these activities took place
- Analysis of the number of people participating in cancer screening promotion activities and whether these were likely to come from underserved populations
- Analysis of pre and post event/activity cancer screening awareness survey results
- Information on the total costs of setting up and running the community workers training project.

The measures of intention to be screened and understanding of cancer screening do not readily translate into an attributable change in screening uptake. In addition other activities more directly targeted at improving uptake (text messaging cervical screening reminders and use of screening coordinators) inevitably confound the results.

#### Cost effectiveness of all three projects

The purpose of the cost-effectiveness analysis was three-fold:

- To help to emphasise the message of the value of achieving the performance targets for the three screening programmes which are published nationally (Department of Health and Social Care 2019)
- To demonstrate to stakeholders whether these interventions are effective and costeffective solutions to enable the targets to be met.
- To highlight where the on-going costs and benefits of these programmes might impact the local health and care system.

# Appendix 3: Literature review

#### Introduction

A high level of participation is needed if screening programmes are to achieve their aim of reducing mortality. The Cheshire and Merseyside Cancer Screening Programme includes three initiatives to improve uptake/coverage:

- The cervical screening improvement project will use text message reminders to increase uptake of cervical screening
- The bowel/breast screening improvement project will use screening co-ordinators/ patient navigators to hold conversations about participating in bowel/breast screening
- The screening community engagement project will use an online education and training package for community workers and funding for community engagement to raise awareness of screening programmes in underserved populations.

Our evaluation of these projects includes three literature reviews summarising the evidence base for the use of these types of initiatives to improve uptake/coverage. In this literature review we identify, describe and summarise the evidence relating to the effectiveness of these interventions.

#### Methodology

The review questions are:

- 1. What is the effectiveness of using text messaging to improve the uptake of cervical cancer screening?
- 2. What is the effectiveness of using screening co-ordinators/ patient navigators to improve the uptake of breast and bowel cancer screening?
- 3. What is the effectiveness of using community engagement to improve the uptake of population screening in underserved populations?

Searches of 3 databases (Medline, Embase and Cochrane Library) were informed by the PICOs and were conducted on 17th February 2020. They included studies published in English between 1st January 2010 and 17th February 2020.

We also conducted targeted internet searches for grey literature. This included searches of NICE Evidence and the TRIPdatabase (February 2020) and Google searches (March 2020). We applied a pre-specified rule for when to stop screening the results of Google searches (i.e. the first 50 results). We also accepted any grey literature reports relating to known relevant projects supplied by the project team.

One reviewer screened all search results and assessed their eligibility for inclusion. Full
papers were ordered for papers that met the inclusion criteria or where eligibility was
unclear from the abstract. UK studies, and studies with applicability to the Project
interventions were prioritised.

The effectiveness of using text messaging to improve the uptake of cervical cancer screening

#### The evidence base

The search for published evidence identified three relevant studies on the effectiveness of text messaging to improve the uptake of cervical cancer screening. Two further studies were identified by a search for grey literature. These studies included three UK studies, all of which were conducted in London. There was one randomised controlled trial (RCT) (Huff et al 2017), a service evaluation (Ryan et al 2019) and unpublished results from a London pilot study. The other studies identified were from a Portuguese RCT about the effectiveness and cost effectiveness of a text message intervention (Firmino-Machado et al 2019a; 2019b).

Other studies identified by the searches were excluded because:

- They did not report any results on the effectiveness of text messaging
- They related to attendance at a diagnostic clinic following a positive screening result
- Text messages were included as part of a wide range of interventions, with no separate results
- The reminders were sent after an opportunistic referral to screening, rather than as part of a population screening programme
- The study included multiple individually tailored text messages with interactive elements, aimed at increasing knowledge and awareness

In two UK studies, uptake increased by approximately four or five percent following either a simple reminder or a GP endorsement text message. However, in the UK RCT, other forms of text message content e.g., social norm or gain/loss framed messages did not result in a statistically significant increase in uptake compared to no text message.

In the third UK study, between 5% and 13% of women in different age groups booked an appointment for screening following a text reminder message, however the proportion of women who attended the appointment is unknown.

In the Portuguese RCT, uptake improved by approximately 11.3% compared to a written invitation letter, however this study included follow-up text messages and automated phone calls to women who did not respond to the initial text message.

Limited details were available for many of these studies and they varied considerably in sample size and the exact nature of the text message intervention. All three of the UK studies were conducted in London. There is some evidence that text messaging may be most effective in younger age groups

In the table below, evidence from 3 UK initiatives is presented first, followed by details of a Portuguese RCT and a US study.					
Study	Population	Intervention / comparator	Outcomes	Appraisal	
Huf et al 2017 RCT	Women aged 25 to 64 years, in a low-	For women aged 30-64: Intervention:	Women screened by 18 weeks:	This RCT was only available as a conference abstract	
Aim: to test the effect of modifying text message reminder content on cervical screening uptake UK	coverage London borough, invited for cervical cancer screening between February 2015 and October 2015 N=13,587	<ul> <li>6 groups with different forms of text message reminders:</li> <li>1. A simple reminder (1,522)</li> <li>2. GP endorsement (n=1,493)</li> <li>3. Total social norms messages<sup>6</sup> (n=1,514)</li> <li>4. Proportional social norms messages (n=1,488)</li> </ul>	For both age groups, a text message with GP endorsement significantly increased uptake compared to no text message: For women aged 30- 64: GP endorsement text message (38.4%) vs no text message reminder (34.4%) (OR 1.19, 95%CI 1.03 to 1.38, p=0.02)	and therefore provided limited detail for critical appraisal Intention to treat analysis was performed. The analysis was adjusted for age and deprivation The study was conducted in an area of London (Hillingdon) with low- coverage	

Table 1: Text messaging to improve the uptake of cervical cancer screening

<sup>6</sup> Communicating screening rates of peers

		<ul> <li>5. Gain-framed messages<sup>7</sup> (1,560)</li> <li>6. Loss-framed messages<sup>8</sup> (n=1,507)</li> <li>Comparator: No text message reminder (n=1,568)</li> </ul>	For women aged 25- 29: GP endorsement text message (31.4%) vs no text message reminder (26.4%) (OR 1.29, 95%CI 1.09 to 1.51, p=0.002)	
		For women aged 25-29: Intervention: GP endorsement text message (n=1,482) Comparator: No text message reminder (n=1,453)	For women aged 30- 64 a simple text message reminder significantly increased uptake compared to no text message: Simple reminder (38.1%) vs no text message reminder (34.4%) (OR 1.18, 95%CI 1.02 to 1.37, p=0.03)	
			No other significant differences between the different forms of text message reminder and no text message reminder	
Ryan et al	Women aged	Intervention:	158 women (10.8%,	This cohort study did
2019	25 to 64 years	Women were sent	95%CI 9.2 to 12.5)	not include a
Service	≥6 months overdue for	a text message informing them that	appointment within 5	comparator so does
evaluation	cervical	they were overdue	months. Most women	information about
A :	screening in 3	for screening and	(72%) booked an	the effectiveness of
the feasibility	a deprived	download an app to	using the app	reminders compared
of an app to	East London	book an		to no reminder
book	borough	appointment	Subgroups of women	
for women	N=1.464	Comparator:	wno роокеа an appointment (%)	reported was the
overdue for	1,101	None	Age:	number of women
cervical	Mean age:		• 25-34 (n=790):	who booked an
screening	10.3)		9.6 to 14.2)	appointment. The authors were not
5	,		• 35-44 (n=354):	able to confirm
UK			9.7 to 16.9)	whether women
			• 45-54 (n=166):	appointment and
			6.6% (95%Cl 3.4 to 11 5)	were screened
			• 55-64 (n=154):	The study was
			5.2% (95%Cl	conducted in an area
			2.0 10 10.07	of East London with
				nigh deprivation

<sup>7</sup> Lives saved associated with participating in screening
 <sup>8</sup> Lives lost associated with participating in screening

			Deprivation: • IMD 1 (n=297)	
			<ul> <li>10.1% (95%Cl 6.9 to 14.1)</li> <li>IMD 2 (n=749): 11.2% (95%Cl 9.0 to 13.7)</li> <li>IMD 3 (n=359): 10.3% (95%Cl 7.4 to 13.9)</li> <li>IMD 4 (n=28): 7.1% (95%Cl 0.9 to 23.5)</li> <li>Very few women were from IMD 5 -10 (least deprived deciles). 28 women were missing data on IMD</li> </ul>	
Unpublished results of the digital text messaging London pilot Text message reminders implemented across all London boroughs UK	All women aged 25 to 64 invited for cervical cancer screening between September 2018 and March 2019 Approximately 288,000 women received a text message	Intervention: Text message reminder Comparator: Unclear. This is likely to be the time period prior to the introduction of text message reminders	IMDFor women who received a text reminder, uptake at 18 weeks was higher by 4.8%For subgroups uptake was higher by: Age• 25-49: 4.8% • 50-64: 5.9%The average time between invitation and screening was 54 days with an invitation letter and text reminder, and 71 days for an invitation letter only	This information was taken from a presentation given by the Cervical Screening Task & Finish Group in November 2019 The data reported is the increase in uptake rather than the actual uptake The study was conducted in London. 97% of London GP practices participated
Firmino- Machado et al 2019a;	Women aged 25 to 49 years eligible for	Intervention: All patients received at least 1	Effectiveness Proportion of women screened (assessed	This RCT tested the effectiveness of a 3- step intervention,
Firmino-	cervical cancer	text message with a	45 days after the	including text
Machado et al	screening	proposed	initial invitation):	messages and an
20130	13 Portuguese	and were asked to	Intention-to treat	call (step 1), manual
RCT with cost	primary health	confirm their	analysis	phone calls (step 2)
ettectiveness	care units in 2	attendance and a	A significantly higher	and face-to-face
anarysis	Portugal	24-48 hours before	received cervical	Only outcomes
Aim: to assess	(adherence to	the scheduled	screening following	relating to the first
the	cervical	appointment	the text messages/	step on the
of an	the 2 areas	request an	(39.0%) than after the	reported
intervention to	was 30% and	alternative	written letter (25.7%)	
improve adherence to	60% respectively)	appointment date). n=605	(OR 1.87, 95%CI	Intention-to-treat and per-protocol

cervical 1.46 to 2.39.	analyses were
cancer N=1,220 The initial invitation p<0.001)	reported. The per-
screening text message was	protocol analysis
Mean age: repeated up to 2 Per-protocol analysis	accounted for non-
Portugal Intervention: times, if an (Intervention (n=517)	, delivery of text
34.0 years (SD appointment was comparator (n=609))	messages e.g. due
7.9) not confirmed A significantly higher	to an invalid phone
Comparator: women also proportion of women	number. The
35.2 years (SD received an received cervical	analysis was
7.4) automated phone screening following	adjusted for age,
call invitation up to the text messages/	education,
3 times automated phone ca	ll household size,
(42.9%) than after th	e employment status,
<b>Comparator:</b> written letter (25.9%)	occupation, health
Written invitation (OR 2.14, 95%CI	care area,
letter (standard 1.66 to 2.77,	deprivation and
care) p<0.001)	previous
n=615	participation in
Costs	organised screening
From the provider	
perspective:	Portugal has a
Mean 5 vear cos	t universal, National
per woman	Health System and
invited for text	provides population
message	screening free of
intervention:	charge. Cervical
€23.9	cancer screening is
Mean 5 year cos	t implemented by the
per woman	primary health care
Invited for writter	units with systematic
letter comparato	written letter
€23.2 • Moon short form	invitations every 5
	years to women
invitation costs)	aged 25 to 65 years
Der woman	- ,
invited: €0.1	Cost effectiveness
Mean short-term	was assessed for a
cost (only writter	short term and 5
letter invitation	year time horizon
costs) per woma	n and from the
invited: €0.9	provider and societal
	perspective, using
From the societal	2018 prices. Data on
perspective:	effectiveness was
Mean 5 year cos	t aken from the RCT,
per woman	however the most
invited for text	optimistic estimates
message	of effectiveness
	were used
	+
IViean 5 year cos     Der woman	Costs included
invited for writter	materials, software
letter comparato	and screening and
€27.6	treatment costs
Mean short-term	
cost (only text	ICERs were only
invitation costs)	calculated from the
per woman	perspective of all
invited: €3.1	interventions tested

		Moon short torm	in this RCT some of		
			which are out of		
		cost (only written	which are out of		
		letter invitation	scope		
		costs) per woman			
		invited: €3.2			
		Cost-effectiveness			
		Comparator			
		(written letter)			
		QALY per woman			
		invited: 4.61			
		Intervention (text			
		necosageo) Q/E1			
		invited: 4.61			
		invited. 4.01			
		The OAL Ve wore the			
		The QALTS were the			
		same from a provider			
		and societal			
		perspective			
		ICER and cost per			
		woman screened			
		were not reported for			
		the intervention of			
		interest			
			a maio a al la contra lla al triat		
Ci – confidence interval; GP – ge	CI – confidence interval; GP – general practitioner; OR – odds ratio; RCT – randomised controlled trial;				
SD – standard deviation					

# The effectiveness of using screening co-ordinators/ patient navigators to improve the uptake of breast and bowel cancer screening

#### The evidence base

The search for published evidence identified four relevant studies on the effectiveness of patient navigation to improve the uptake of breast and bowel cancer screening. No additional studies were found by a search for grey literature.

One RCT concerning bowel screening was conducted in Tyneside (McGregor et al 2019) and two pilot studies concerning breast or bowel screening were conducted in London (Graham et al 2014; Raime et al 2012). A French RCT and cost-effectiveness analysis on bowel cancer screening was also identified (De Mil et al 2018).

Other studies identified by the searches were excluded because:

- They did not report any results on the effectiveness of patient navigation
- The screening context described had limited applicability to the UK
- They related to navigation for patients who had received a positive screening result
- The patient navigation intervention was extensive and/or combined with a range of other interventions

All included studies targeted non-responders/ non-attenders for screening with navigation that primarily included attempting to contact patients by telephone. The French RCT demonstrated an improved uptake of approximately 3% for faecal occult blood test amongst non-responders for navigation compared to usual care. The UK RCT did not demonstrate a benefit to navigation above usual care for bowel scope screening. However, limitations in the design and context of the RCT may have limited its ability to demonstrate effectiveness.

The two UK pilot studies did not include a comparator. Raime et al (2012) reported that 34% of participants received a mammogram following navigation. Graham et al reported that 19% of participants completed FOBT screening following navigation.

The studies varied in size and there was some variation in the extent of the patient navigation intervention. Only the French RCT provided evidence for the extent to which patient navigation may increase uptake above usual care.

Study	Population	Intervention /	Outcomes
olday	ropulation	comparator	Cultonico
McGregor et al	Individuals (men and	Intervention:	Most study participants attended
2019	women aged 55	Patient navigation:	their initial appointment
	years) invited for	patients who did not	(intervention group 79.8%,
RCT	bowel scope	confirm or attend their	comparator group 79.1%).
	screening at South	screening appointment	Therefore only 22 patients were
Aim: to assess	Tyneside District	received a phone call to	eligible to receive patient
the feasibility	Hospital between	elicit their reasons for	navigation from the 109
of patient	May and October	non-attendance and	randomised to this group
navigation to	2015	offer educational,	
facilitate		practical and emotional	Only 2 of the 22 patients eligible
uptake of	N=152	support if required.	were successfully contacted by
bowel scope		Patient navigation was	the patient navigators. For these
screening		also offered to people	patients the navigation was brief
		who contacted the	(1 had been referred for
UK		screening centre to	investigation by their GP and 1
		cancel their appointment	had forgotten their appointment
		without intention to	and immediately re-booked)
		rebook (n=109)	
			Of the 20 eligible patients not
		The patient navigators	successfully contacted:
		were specialist	• 10 did not answer any call
		screening practitioners,	attempts
		based in screening	4 had an invalid number
		centres	3 were lost to follow-up due to
		Compository	<ul> <li>3 answered but declined to</li> </ul>
			• Sanswered but declined to
		Usual care (n=43)	participate
		Usual care consisted of	3 months after the last call
		a pre-invitation letter.	attempt, 3 patients from the
		followed by a bowel	patient navigation group (1 of
		scope screening	whom had been successfully
		appointment sent 2	contacted) and 1 patient from the
		weeks later to	control group had attended
		consenting individuals. If	screening. Screening attendance
		no confirmation was	for study participants was
		received within 2 weeks	therefore 82.6% for the
		a reminder was sent. If	intervention group and 81.4% for
		confirmation was not	the control group
		received in a further 2	
		weeks a cancellation	Costs
		letter was sent	Mean cost per participant:
			Patient navigation: £18.92
			Usual care: £12.10

Pilot intervention	Non-responders to bowel cancer screening from a GP practice in Camden, between August	Intervention: Monthly calls to all non- responders to identify reasons for non- participation and	Control 73 non-responders, 38% could not be contacted (46% of these were due to an incorrect or no phone number)
Aim: to increase	2013 and February 2014. Non-	encourage participation. A follow-up call was	28 of the patients contacted agreed to be screened and 14
uptake of bowel cancer	responders had failed to return a	made to people who agreed to participate but	completed screening (14/73 = 19.2%)
screening amongst patients at a	completed FOBT screening kit	had not returned a screening kit. Calls were made by a doctor or	15 patients refused screening following a call
London	N=75	the phone number on file was incorrect a letter	Call outcomes were similar for calls made by the doctor or the
UK		was sent (n=73)	health care assistant
		Awareness raising with clinical staff including giving them a bowel cancer pack and alerts	
		on the notes of non- responders to promote opportunistic	
Do Mil et al	People aged 50 to	Intervention:	Untako
2018	74 years living in 3	Patient navigation	Patient navigation was associated
RCT and cost	France between	personalised support	increase in screening of 3.3%
effectiveness	April 2011 and April	provided by 3 trained	(95%CI 1 5% to 5 0%) (24 4% vs
onconverieue	2013	social workers for	21.1%, p=0.003)
Aim: to		individuals with an	
evaluate the	N=16,250	available phone number	Uptake by subgroup
effectiveness	,	who had not responded	For affluent participants, uptake
and cost	Mean age was not	during the 4 months	was significantly higher in the
effectiveness	reported, but there	after the initial invitation.	navigation group (26.1% vs
of a patient	were more	Participants were initially	22.0%, p=0.01)
navigation	participants in	contacted by mail with	
programme in	younger age groups	an invitation to phone or	For deprived participants, there
Northern	(50-60 years)	email the patient	was no statistically significant
France		navigator and then	difference in uptake (22.9% vs
France		received a phone call 10	∠0.3%, p=0.07)
riance		identifying barriers to	Costs
		screening. Navigation	The total cost of 2 years of patient
		could also include home	navigation was €321,787 with
		visits and mailing of	70% consisting of navigator
		FOBT kit. Participants	wages
		who could not be	
		contacted after 3 or 4	Each (of 3) navigators attended
		attempts were sent a	about 30 participants per week
		postal reminder with a	Wost contact took place by phone
		pre-paid reply envelope	and email (13 nome visits were
		be contacted (n=8 105)	
			The average cost per person was
		Comparator:	€39.70 ± 4.38
		Usual screening	
		consisting of a mailed	

invitation to see their GP	The ICER for the cost per
to get a FOBT kit if	additional individual screened by
indicated. Non-	navigation compared with usual
responders receive a	care was €1,212 (95%Cl 872 to
mailed reminder with a	1,978) for all participants; €1,527
FOBT kit, 3 to 4 months	(95%CI 914 to 4,558) among
after the initial invitation	deprived participants and €969
(n=8,145)	(95%CI 659 to 1,822) among
	affluent participants
	In sensitivity analysis, the ICER
	ranged from €778 to €2,738 for
	the lower and upper bounds
	(95%) of the CI for effectiveness
	The ICER decreased 71% if
	navigators were unpaid
	volunteers (€355)

CI - confidence intervals; FOBT - faecal occult blood test; ICER - incremental cost effectiveness ratio

# The effectiveness of using community engagement to improve the uptake of population screening in underserved populations

#### The evidence base

The search for published evidence identified three relevant studies on the effectiveness of using community engagement to improve the uptake of population screening. No additional studies were found by a search for grey literature.

These studies were conducted in the US and reported an intervention consisting of training for lay health workers followed by the delivery of an educational programme for local communities. Nguyen et al (2010) targeted Chinese Americans and focused on bowel cancer screening. Rodriguez et al (2019) targeted African Americans and focused on breast and cervical cancer. Berger et al (2017) targeted Chinese and Vietnamese Americans and focused on breast cancer.

The WHO definition of lay health workers is "those who live in a community, are selected by and accountable to it and work after receiving a short, defined training" Nguyen et al (2010).

Other studies identified by the searches were excluded because they were about the feasibility and development of a (non-online) training programme and did not include outcomes from community engagement.

Nguyen et al (2010) and Rodriguez et al (2019) demonstrated an improvement in knowledge following educational sessions. Some information was available on screening uptake, with Nguyen et al reporting a 56% increase in FOBT screening five to six months later and Rodriguez et al (2019) reporting a 33% increase in screening uptake for breast or cervical cancer amongst a sample of women who received the educational programme and were followed-up two months later. Berger et al (2017) showed limited improvements of knowledge but was affected by a high level of baseline knowledge and past screening receipt amongst workshop attendees.

No UK studies were identified. The applicability of the study populations to the UK is uncertain. Limited information was available on screening uptake following intervention and the available information was self-reported.

The studies all had small sample sizes, and varied in the nature of the training received by lay health workers. None of the studies used online training. The educational programmes delivered to participants were similar in that they were adapted versions of national curricula.

StudyPopulationInterventionOutcomesAppraisalNguyen et al 2010Immigrant ChineseChinese American lay health workers (n=8) received 12 about colorectal aged ≥50Of 335 people approached by the lay health workers, aged ≥50This study was conducted amongst the Chinese American immigrant population in one area of the USAim: to implement a lay health worker colorectal colorectalFrancisco aged ≥50about colorectal cancer, screening hour training vas delivered in 2 6- hour training1 person dropped out whilst completing the pre-intervention surveyScreening recommendations in the US for people aged 50 to 75 are:Nguyen et al 20108 people worker colorectal cancerEach lay health workers77 of the 81 praticipants recruited completed both educational sessions. These used a flipchart, worker, r3 of intervention survey70 participants participants colorectal al ay health worker, r3 of intervention session from a lay health worker, r3 of otorectal colorectal cancer81 people educational sessions. These used a flipchart, worker symptoms, risk factors and colorectal cancer, <b< th=""></b<>
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being your back, he heard of polyps:
screening test. The 2 • Theatd of polyps.
Sessions were held Fatty diet as risk
6-8 weeks apart factor: 36 6% vs
Lay nealth workers
also made follow-up factor: 12.2% vs
calls after each 61.0%
session to answer     Believe that
questions, provide screening tests
encouragement and can prevent
ascertain if colorectal
participants had cancer: 39.0% vs
received screening 82.9%
yet
colorectal
cancer: 31.7% vs
65.9%
Awareness of     CODT: 04 70/
FUBI: 31.7% VS 07.1%

			<ul> <li>Awareness of sigmoidoscopy: 0% vs 97.1%</li> <li>Awareness of colonoscopy: 38.4% vs 97.1%</li> <li>Knowledge of other risk factors was also significantly improved e.g. hereditary, smoking, lack of physical activity, constipation</li> </ul>	
			and toxins <b>Screening intent</b> significantly improved pre- intervention vs post- intervention (p<0.05): • Thought about	
			<ul> <li>obtaining an FOBT: 33.3% vs 53.3%</li> <li>Thought about obtaining a colonoscopy: 24.7% vs 43.3%</li> <li>Planned on obtaining an</li> </ul>	
			FOBT in the next 12 months: 42.5% vs 60.0% Other screening intent questions were	
			<ul> <li>Screening uptake:</li> <li>FOBT: 55.7%</li> <li>Sigmoidoscopy: 7.1%</li> <li>Colonoscopy: 7.1%</li> </ul>	
Rodriguez et al 2019 Pilot study on effectiveness	African women aged ≥18 years resident in 3 sites in the	Intervention: Lay health advisors received training over a 2-month period	24 individuals were trained. 31 educational programmes reached 332 community	The project used an updated version of the National Witness Project educational programme curriculum
Aim: to determine the suitability and effectiveness of a new	New York and Little Rock) between October	Community-based lay health advisor programme using group education, navigation and	Breast cancer knowledge improved from pre-to post-	Not all participants answered all pre- and post-intervention questions
curriculum amongst participants	2016 and January 2017 were	survivor narratives	intervention (52.8% vs 88.7%, mean	The main focus of the study was to assess a new programme

attending an educational programme US	eligible to receive the community education programme, focusing on breast and cervical cancer N=332 Most participants (56%) were aged ≥50 years	Mean programme length: 80 mins (SD 12.85) Participants completed a pre- intervention survey Community participants eligible for breast and cervical cancer screening were contacted 2 weeks after the educational programme to assess knowledge, retention, dissemination, risk perception, self- efficacy and intent for breast and cervical screening. Participants non- adherent to screening guidelines were contacted again at 2 months to assess dissemination of programme content and screening intent/ completion	change 35.9%, p≤0.001) (n=134) Cervical cancer knowledge improved from pre-to post- intervention (57.7% vs 94.4%, mean change 36.8%, p≤0.001) (n=180) Follow-up surveys with a 20% sample of previously non- adherent women who attended an education programme demonstrated a 33% screening rate after 2 months	curriculum, and its impact on knowledge. It did not specifically look at screening intent and uptake
Berger et al 2017 Community engagement project Aim: to evaluate a peer-led community programme promoting cancer prevention by improving breast cancer screening rates US	Chinese and Vietnamese women living in the Greater Boston area N=252 Participants age ranged from <39 to >80 years	Intervention: Coalition building: 15 local agencies were partners in the project and were responsible for recruitment women for workshops 10 Asian women who were cancer survivors or had experienced breast health problems were trained as peer health educators Training consisted of 2 sessions based on a National Asian Women's Health Organization curriculum	252 women participated in 14 workshops. Evaluation data was available from 238 women The study participants had a high baseline knowledge on questions about mammograms and breast cancer risk (88-97%). Most participants had also received a clinical breast examination (69%) or mammogram (59%) in the 12 months prior to the workshop Knowledge in some areas improved	The Asian Breast Cancer Project was started by a breast cancer survivor and included planning and coalition building, community health worker training and a community level intervention with workshops The ability of the intervention to show a positive benefit was limited by the high level of knowledge by participants prior to the workshop The main purpose of the study was to increase knowledge and awareness. It did not specifically look at

adapted from existing evidence- based programmes for cancer prevention activities. Workshops lasted 2 hours Workshop participants completed a questionnaire before and after the	<ul> <li>significantly pre- and post- workshop:</li> <li>Meaning of lumps in the breast (69% vs 80%, p&lt;0.0001)</li> <li>Frequency of clinical breast exam (48% vs 67%, p&lt;0.0001)</li> <li>88% of 192 women who answered the question were willing</li> </ul>	screening intent and uptake
workshop	to get a mammogram	

## Appendix 4: Screening coordinators reporting template

#### Cheshire and Merseyside Screening coordinators action plan template

This template is to be completed as a way of documenting what interventions the screening coordinator will put in place with the aim of improving screening uptake. Each of the interventions can be considered as a mini-project and the template is a way of documenting progress, including, decisions about stopping or starting interventions, challenges, things that worked and problem solving. The first table has been completed using an example of an intervention to show the type of information we are interested in receiving.

Important points to consider when completing the template:

- The 2 columns 'Plan detail' and 'Planned actions' can be completed following conversations with a range of people such as screening managers, local bowel/breast screening programme steering groups, GPs, and ourselves (SPH) to plan what would be a useful intervention and how it would work in practice
- Monthly updates are completed by the screening coordinator detailing progress, challenges and decisions made in relation to the intervention and sent to Champs Support Team Programme Manager.
- The 'measure' section is about how to show whether the intervention is making a difference. This is likely to involve collecting information and data in the form of people's views about screening and the intervention and the numbers of people who have taken up the offer of screening following the intervention. SPH are happy to work through with screening coordinators the most straightforward way of collecting this information. Once SPH have received the information we will analyse it and the results will be reported in the evaluation.
- If you have any queries about completing the template then do get in touch with Cathy Lines at SPH (<u>cathy.lines1@nhs.net</u>)

	Example: Aim of intervention 1	Example: To identify and contact a proportion of women invited for breast screening to explore their concerns about participating in the programme and deliver key messages to address concerns and support them in making an appointment if they wish to do so.									
	Key element	Plan detail	Planned actions	Month 1 progress update	Month 2 progress update						
1	Audience	Agree who to target									
2	How is target audience defined	How will you identify that particular group of people you're targeting									
3	Barriers/Issues	What are the likely barriers or issues for this group									
4	Key messages	What key messages do you want to convey?									
5	Channel	What route will you take to contact the women?									
6	Tool	How will you convey your message?									
7	Timing	When will you implement your activity?									
8	Measure	How will you measure that you've made a difference?									
9	Other element	Anything important about the activity not included above?									

# Appendix 5: Screening coordinators job description

#### Job Title: Breast Screening Coordinator/Bowel Cancer Screening Coordinator AfC Band:4 Hours: 37.5

#### Background

The NHS Long Term Plan details ambitious aims for the detection and treatment of cancer, with Cancer Alliances playing a key role in the delivery.

The plan highlights that by 2028 an extra 55,000 people each year will survive for five years or more following their cancer diagnoses three in four cancers (75 per cent) will be diagnosed at an early stage

The aim across Cheshire and Merseyside is to improve screening uptake and coverage and reduce the variation in cancer screening programmes focussed on population groups who are particularly vulnerable to screening inequalities.

The role will engage directly with participants and support them to participate in screening

The post holder will demonstrate excellent organisational skills, must be flexible in approach, able to exercise initiative and demonstrate a consistently high standard of professionalism, being aware of the need for confidentiality and integrity. The post holder will have excellent communication skills and be willing to undertake on-going training and development. In addition, the post holder will be able to signpost clients/participants to the relevant sources of support and information appropriate to their needs.

A key aspect of the role involves daily and direct (e.g. face to face and telephone) communication with participants/clients, relatives, carers, and other health and social care professionals. The information and nature of the communication required is sensitive due to the nature of screening for cancer. Communication in this context requires a high degree of empathy, understanding, diplomacy, honesty and integrity and for this reason post holder will have excellent communication skills and be willing to undertake training and development.

It is expected that the post holder can work autonomously and as part of a team, using their own initiative and within a specialised team.

#### Key Duties and Responsibilities

These duties and responsibilities listed below are not an exhaustive list and maybe subject to change depending upon business need. In addition, all staff are expected to act in accordance with the values and behaviours of the Trust.

- 1. Contribute to the increase in uptake and coverage for screening by telephoning identified nonresponders (if required and where applicable) for example, those who have been called for the first time and have not attended, looking for ways to support attendance and undertakes surveys or audits to assess effectiveness of different aspects of the service.
- 2. Contribute to a reduction in non-responders and DNAs for screening and assessment, if required and applicable
- 3. Proactively contact participants (where applicable) who have been called for the first time, to ask if they are intending to attend screening. Offer information and support if required or obtain an understanding as to the reasons why if they are not planning to attend.
- 4. In collaboration with the Programme Manager/Office Manager, use site specific uptake data and demographic data to develop an understanding of the population groups not attending for screening i.e. those from protected characteristic groups and the barriers that those population groups face in accessing screening services.

- 5. Provide help to participants such as giving detail behind correspondence/helping the participant understand the information they are given, offering emotional support, reminding the client of appointments and rearranging them on the client's behalf if necessary.
- 6. Answer queries in relation to their appointment, finding advice from appropriate source where needed
- 7. Provide comprehensive and effective health promotion support in identifying, developing and implementing specific approaches in relation to screening to raise awareness of and to increase uptake and coverage rates.
- 8. Gather evidence on why the local eligible population choose not to attend/participate in cancer screening
- 9. Work closely with GP practices and to liaise with health care professionals and voluntary organisations in organising promotional information and events in promoting breast screening for hard to reach groups e.g. disabilities, Black and Ethnic Minority Communities.
- 10. Target lower uptake practices for breast screening; to drive uptake up and to increase the number of people who attend.
- 11. Supporting the Programme Manager/Office Manager to maintain an accurate recording system to monitor performance, to demonstrate trends and to analyse information in compiling detailed reports.
- 12. Maintain client/participant information in accordance with the national and local guidelines of the and local governance requirements (where appropriate)
- 13. Develop and support the delivery of screening promotional material to be available in GP practices and other appropriate community locations, websites and social media.
- 14. Provide regular progress reports to the Programme Manager.
- 15. Work collaboratively with local and national agencies such as CRUK to support local initiatives to improve outcomes and increase uptake.
- 16. Undertake Health Promotional visits to GP practices in collaboration with the Programme Manager ensuring initiatives are co-ordinated to support the programme.
- 17. Work collaboratively on behalf of the breast screening programmes in GP practices, to encourage GP's and primary care staff to acknowledge the importance of their role and endorsement in screening uptake and help them target non-attenders.
- 18. Understands the boundary of the role and can escalate queries to the appropriate health professional
- 19. Working in the community to support screening activities and delivering key messaging

#### **Equality and Diversity**

- 20. Maintain an up to date knowledge of the parameters of legislation and Trust Policies and procedures related to equality and diversity.
- 21. Treat everyone equally and with dignity and respect and acknowledge others' different perspectives.
- 22. Recognise that people are different and makes sure they do not discriminate against other people.

#### Data & Information

- 23. Applies the principles of data protection working within legal limitations with access and storage of data
- 24. Understands and complies with data standards and confidentiality specific to the organisation
- 25. Participates in audits and quality improvements

### Communication and working relationships

Key Relationships								
Internal	External							
Clinical Director, Programme Manager, Unit Manager, Directorate Manager, Lead Administrator	GP's, Practice Managers, Practice Staff							
Cheshire & Merseyside Champs Public Health Collaborative	Public Health England (PHE) Screening and Immunisation Teams (SIT), Clinical Commissioning Groups (CCG), Health Improvement Officers, Cancer Champions,							
	Screening Quality Assurance Service – North (SQAS)							
Patient and Public Engagement Team, Communications Team and other staff within the Trust as appropriate	Public, carers, visitors and other service users							

#### **Person Specification**

	Essential Criteria	Desirable Criteria
Qualifications	<ul> <li>Level 3 Health or Social Care qualification or equivalent (e.g. NVQ or similar)</li> <li>ECDL or equivalent experience</li> <li>Good general education with GCSE English and Mathematics at grade C or above</li> </ul>	<ul> <li>Level 4 Health or Social Care Qualification (e.g. Foundation degree)</li> <li>Evidence of continued role development</li> </ul>
Knowledge & Experience	<ul> <li>A minimum of 2 years' experience working in a public facing role</li> <li>The ability to liaise with a variety of people at all levels</li> <li>Understands confidentiality</li> <li>Some knowledge of the principles of screening and informed consent</li> </ul>	<ul> <li>Previous medical secretarial or administrative experience</li> <li>Some knowledge of breast or bowel cancer screening</li> </ul>
Skills Additional	<ul> <li>Efficient in the use of Microsoft packages- Word, Excel, PowerPoint and Outlook and the internet</li> <li>Ability to produce clear written reports</li> <li>Possess excellent communication skills – ability to communicate verbally and non-verbally with people daily</li> <li>Effective organisational skills</li> <li>Ability to work across a variety of sites across the Breast and Bowel Screening catchment areas</li> <li>Able to work on own initiative and work without supervision</li> <li>Able to communicate with a range of people, demonstrating empathy and understanding</li> <li>Ability to analyse use of resources against requirements</li> <li>Good problem-solving skills</li> <li>Flexible and adaptable in approach</li> <li>An interest in screening and health promotion is essential.</li> <li>Ability to travel independently across the area of the</li> </ul>	
Method of Assessment	programme essential Application form/interview	
, 100000mont		

# Screening coordinators role matrix

Bowel Cancer Screening Coordinator/ Breast Screening Coordinator Role Matrix												
Purpose Provision of a dedicated Screening Coordinator who is hosted by the XX screening programme. The post holder will be responsible for improving the uptake in breast/bowel screening and reducing health inequalities, working as part of the screening programme team, and in partnership with Primary Care and the community, supporting screening specific projects that will raise awareness of and improve the uptake of screening activity.												
KPI's	KPI	Acceptable (%)	Achievable	e (%)		Air	n					
(SPH to supply)	XX							2020/21				
	XX											
Goal		Suggested Activities		Chall	enges/Risks	Mit	tigations		Par	tners	Time/Resources	
The screening coordi collaboratively with G support the improven coverage Encourage practice s acknowledge the imp role in endorsing the programme In collaboration with f Programme Managet reports to identify are	inator will work P practices to nent in uptake and staff to portance of their screening the XX Screening r use data and pas with the lowest incoundity in	<ol> <li>Encouraging GP pr contact identified no responders</li> <li>Encourage practice learning (if appropri 3. Encourage GP prac identify those about eligible for their first episode and identify screening</li> <li>Conduct inequalitie audit to compare up coverage</li> <li>Use data to target s</li> </ol>	actices to on e staff iate) ctices to t to become t screening y barriers to s/baseline otake and specific	•	Information governance agreements Screening ethics Engagement with the public Ensure contact is appropriate and timely Engagement with practice staff Availability of up to date accurate data that includes protected characteristics for BSP/BCSP clients/participants	•	Clarify da agreeme Ensure a appropria Ensure p has beer ensure c appropria Ensure p Explore s and iden suitable	ata sharing onts advice is ate patient/participant on reviewed to ontact is ate inks with CRUK to iractice learning sources of data tify those most at a local level ation with	•	GPs/practice staff CCGs Screening Programmes CRUK PHE/NHSE/I CCG GP Leads LA Public Health Teams	Ongoing: GP admin staff time. Practice staff being released for learning Ongoing: initial data analysis from existing available	
uptake and areas of i screening and suppo	nequality in rt targeted activity	<ol> <li>Ose data to trace in groups for screenin improvement</li> <li>Provide support to l performing GP practo improve uptake</li> <li>Audit reasons for maccepting first screeninvitation but then tain subsequent roun</li> </ol>	low ctice areas ot ening aking part ds	•	Lack of engagement Socioeconomic barriers Language barriers	•	commun Use of translato	rs/interpreters	•	Action on Cancer and other local stakeholder groups C&M Screening Coordinator	sources, such as Fingertips, Power BI tools	
The screening coordi effective health prom raise awareness of X support improvement coverage	inator will provide otion support to X screening and t in uptake and	<ol> <li>Collaborative worki behalf of the screer programmes with th screening and Imm team and agencies support local initiati and ensure joined u</li> </ol>	ng on hing unisation (CRUK) to ves up working	•	Duplication of work Silo working which could lead to different local outcomes Organisational priorities Current pressures on BSP/BCSP that may have an effect on participant/client experience	•	Establish to ensure outcome the XX s program	n joined up working e effective s and supportive of creening me	•	Screening and immunisation teams CRUK GP Practices LA Public Health Teams	Ongoing: support from Programme Manager/Office Manager. Supporting local and regional	

	2. Working with the Programme Manager and lead SSP to coordinate health promotion activities with practices ensuring joined up working			C&M Screening Coordinators	awareness events/campaigns
The screening coordinator will work collaboratively with a range of stakeholders including, but not limited to, Champs Public Health Collaborative, NHSE/I, GP Practices and Leads, CRUK, Action on Cancer in Cheshire, LA Public Health Teams	<ol> <li>Participate in regular meeting with the XX Screening Team</li> <li>Participate with other C&amp;M Screening Coordinators in a peer support network with Champs to collaborate on best practice</li> <li>Attend relevant training and meetings linked to the role</li> <li>Produce updates/reports</li> </ol>	<ul> <li>Duplication of work</li> <li>Organisational priorities</li> <li>Stakeholder management</li> <li>Clarity of roles/responsibilities in relation to specific projects</li> </ul>	<ul> <li>Regular meetings with other Screening Coordinators</li> <li>Regular communication with stakeholders</li> <li>Regular reporting to the XX screening team and Champs</li> </ul>	<ul> <li>C&amp;M Screening coordinators</li> <li>XX Screening Teams</li> <li>GP Leads/Practices</li> <li>NHSE/I</li> <li>Champs</li> <li>LA Public Health Teams</li> <li>Local Cancer Groups</li> </ul>	Ongoing: regular meetings with the C&M screening coordinator peer support network and Champs. Support to Screening Team activities

### Appendix 6: Breast and bowel screening project case studies

Case study 1: Warrington, Halton, St Helens and Knowsley Breast Screening Programme: Text and phone reminders

**Case Study** 

#### AIM

To improve screening participation by reminding women to make an appointment to be screened using text messaging and phone calls.

#### CONTEXT

Prior to the pandemic, breast screening programmes sent a fixed appointment to women to attend breast screening with the opportunity to change the appointment if it was inconvenient. There is evidence that a fixed appointments approach results in increased participation in screening programmes, however it also results in a substantial number of empty appointment slots due to people who do not attend (DNA). Following the pandemic breast screening programmes switched to sending open appointment letters requiring women to call to make an appointment which typically results in fewer DNAs. This would maximise the use of appointments in the recovery phase of the screening programme following the pause in screening in March 2020 due to the pandemic. All women invited for screening were listed in a dummy or holding clinic and once they had phoned to make an appointment were transferred to a real clinic.

#### ACTIVITY

Women were invited to make an appointment to be screened by the Warrington, Halton, St Helens and Knowsley Breast Screening Programme with a routine appointment letter. After two weeks women remaining in the holding clinic were sent a reminder text message and after a further week women were called by phone and asked if they wanted to make an appointment.

#### **EVALUATION**

To evaluate this initiative the screening coordinator was asked to record the number of women in the holding clinics at certain time points:

- Time point 0: at the outset when routine invitations were sent
- Time point 1: the day before the text message was sent
- Time point 2: the day before women were contacted by phone
- Time point 3: when the holding clinic was closed

From this data the number of women who had booked an appointment at each different time point was calculated and the overall percentage of women who intended to come for screening by booking an appointment determined.
In order to estimate the proportion of these appointments the women attended, the average DNA rate in clinics from January to September 2021 was determined and this percentage applied to the number of women who had booked an appointment.

#### OUTCOMES

Early data for this initiative was received for 6 holding clinics with a total of 306 women who had been invited for screening and had progressed to 'closed' status.

Following the first routine invitation 46% booked an appointment prior to receiving a text message and 23% booked an appointment over 2 weeks later after receiving a text message and 16% during or after receiving a phone call prior to the clinic closing. Overall 85.8% (261) of the 306 women who had been invited for screening had booked an appointment.

The average attendance at breast screening clinics on four sites between January and September was 95.3%, a DNA rate of 4.7%. If this is applied to the 261 women booking an appointment, then 249 women are likely to participate with 12 who don't attend.

Overall, of the 306 women invited to be screened from these 6 clinics it is estimated that 81.4% will participate. This is a 5.9% increase on the 75.5% uptake reported in the 2019/20 national breast screening returns for the Warrington, Knowsley, Halton, and St Helens Breast Screening Unit.

## Table 1: Outcomes of 306 women invited for screening using text message and phone call reminders.

Women n (%)	Number of women (%)
Time point 0: Women invited to be screened	306
Time point 1: Women booked an appointment after receiving first invitation	141(46%)
Time point 2: Women booked an appointment after receiving text message (2 weeks after first invitation)	71(23%)
Time point 3: Women booked an appointment after phone call (3 weeks after first invitation)	49 (16%)
Total women booked an appointment at close of clinics	261 (85.8%)
Estimate of number (%) of women who may DNA	12 (4.7%)
Estimate of number (%) of women attending screening of 306 invited taking into account those booked and likely DNAs	249 (81.4%)

#### STRENGTHS OF THIS APPROACH

Directly contacting women and reminding them to make a screening appointment is a known method of improving uptake.

#### CHALLENGES AND UNCERTAINTIES

This approach depends on being able to access accurate mobile phone or landline contact details of women invited for screening which may be resource intensive.

Since the pandemic, in order to meet infection control requirements fewer women can be seen in any one clinic and this has inevitably reduced capacity. This means breast screening clinics may be full before the text message is due to be sent to women in the holding clinic and the breast screening programme is unable to achieve the full potential improved uptake.

This is a relatively small sample (6 out of 37 holding clinics set up in November 2021) and it is unclear if this pattern and scale of improved uptake will be consistent in all clinics across the screening round. For example, it is unclear if the 306 women called for screening came from areas of high or low deprivation, or where there were adequate or inadequate transport links and whether women were predominantly white and English speaking or from ethnically diverse areas with English as a second language. These differences in the demography are known to have an impact on uptake of screening and the impact of interventions to improve uptake.

#### SUSTAINABILITY

If the data continues to indicate around a 6% improvement in breast screening uptake, then employing a screening coordinator to implement this initiative may be a sustainable method of improving the early detection of breast cancer.

## Case study 2: Warrington, Halton, St Helens and Knowsley Breast Screening Programme: double fixed appointments- phone reminders Case Study

#### AIM

To improve screening participation for those women eligible for a double length fixed appointment for breast screening by phoning them prior to the appointment date.

#### CONTEXT

Some women eligible for breast screening are offered a longer timed appointment for their mammogram. These women may have learning difficulties, dementia, require a translator, or have physical disabilities that mean a longer appointment is required.

#### METHODOLOGY

Women who require longer appointments were identified from the Breast Screening System before they were invited to participate. Their GP was contacted and relevant information about each woman sought, to understand what she might require in the way of support during the screening appointment.

Approximately one month before the appointment date the screening coordinator called each woman to speak to her or her carer. The purpose of the call was to:

- Check that the appointment date would be convenient
- Advise women on the location and facilities
- Check if it was likely that extra equipment (e.g., hoist, biopsy chair) would be needed
- Offer a familiarity visit (particularly those with learning disabilities so they feel more comfortable with the surroundings on their appointment)
- Check the need for an interpreter provide reassurance of how this will be provided on the day

Following the phone call the letter confirming the agreed details of the appointment was sent to the woman. Up to 3 attempts were made to contact each woman before posting the standard appointment letter with an appointment time.

Data about previous breast screening attendance (when no phone call reminders were made) and attendance of women invited around the same period who didn't receive phone call reminders was captured for comparison.

#### FINDINGS

During June 2022 a total of 35 women invited for special appointments were successfully contacted a month before their appointment and offered support, a reminder of the appointment

and information about breast screening. For comparison a further 66 women were identified and results collated of those not contacted during June.

Of those contacted 30 (86%) attended for an appointment. A total of 28 (80%) of women contacted had previously attended for screening. The table below shows the number of women who were contacted and those where no attempt was made to contact them. Of the 66 women not contacted 54 (84%) attended screening of whom 52 (81%) had attended screening in the previous round.

# Attendance of women eligible for double screening appointments contacted and not contacted during June 2022

Patients invited for longer timed appointments during June 2022	Number	This round June 2022 attended (%)	Previous round 2019 attended (%)
Women contacted in June 2022	35	30(86%)	28(80%)
Women not contacted in June 2022	66	54(84%)	52(81%)
Total	101	84(83%)	80(79%)

It isn't clear if the difference between the uptake of the women contacted compared to those not contacted (2%) is significant, as the sample size is not large. The proportion of women contacted and not contacted in June 2022 was high in both groups and similar during the previous round in 2019.

#### STRENGTHS OF THIS APPROACH

Directly contacting women, ensuring their appointment is convenient, answering any queries and offering support is a known method of improving uptake.

#### CHALLENGES AND UNCERTAINTIES

This is a resource intensive intervention as phone numbers need to be manually found on the Breast Screening System. There may be IT solutions that could make this process quicker and less prone to possible error.

The women eligible for screening with a double appointment in June 2022 had already shown a high rate of attendance during the previous 2019 screening round (80%-81%). It will be important to target this type of intervention at women from GP practices where uptake has historically been lower to ensure an effective use of screening coordinator time.

#### SUSTAINABILITY

Further testing of this intervention to see how it could be implemented in the most effective way will be important. If used this intervention should be targeted at women eligible for double appointments from GP practices with the lowest uptake and evaluated to see if it has made a difference compared to those invited in previous screening rounds. IT solutions to identify contact phone numbers to avoid manual extraction of the information would reduce the time of screening coordinators in data cleaning.

## Case study 3: Liverpool, Knowsley and Sefton Breast Screening Programme: Double fixed appointments - phone reminders

**Case Study** 

#### AIM

To improve screening participation for those women sent a double length fixed appointment for breast screening by phoning them prior to the appointment date.

#### CONTEXT

Some women eligible for breast screening are offered a longer timed appointment for their mammogram. These women may have learning difficulties, dementia, require a translator, or have physical disabilities that mean a longer appointment is required.

#### METHODOLOGY

Women who require longer appointments were identified from the Breast Screening System before they were invited to participate. Their GP was contacted and relevant information about each woman sought, to understand what she might require in the way of support during the screening appointment.

Following the letter sent to invite the woman for a timed appointment and one to two days before the appointment the screening coordinator would call the woman and speak to her and or her carer. The purpose of the call was to offer support, provide information and remind women of the appointment. Attendance of appointments was monitored and for those that did not attend, a follow up call was made. The purpose of this call was for support if women wanted to re-book their appointment and to ask why they hadn't attended or weren't likely to attend a future breast screening appointment.

#### FINDINGS

From March to April 2022, 326 women invited for longer appointments were contacted. Of those 223 attended and 103 did not attend. Of those who did not attend 14 were successfully followed up with a call and booked a further appointment. Of those re-booking an appointment 7 attended 5 did not attend, one cancelled and one person hadn't yet had their appointment.

Women invited for longer timed appointments	Number	% uptake	
Attended	223	68.4%	
Did not attend	103	31.6%	
Contact calls to DNAs answered	14	13.6%	
Rebooked appointments	14	100%	
Attended re booked appointment	7	50%	
DNA rebooked appointment	5	35.7%	
Cancelled	1	7.1%	
Rebooked appointment outstanding	1	7.1%	

Outcomes of intervention to contact women invited for longer timed appointments

Of those women who were asked why they didn't attend their appointment the following reasons were given:

- Forgot they had an appointment x 2
- Put the appointment letter in the bin
- The person had a learning disability and was not in the right frame of mind to be screened
- Attended the wrong hospital to be screened
- Could not get through to the office to change the appointment
- Reported that they did not receive the appointment letter.

#### STRENGTHS OF THIS APPROACH

Directly contacting women and reminding them to attend their screening appointment and follow up if they DNA is a known method of improving uptake. For women who did not attend their first appointment and were successfully contacted to re-book, 50% attended. If all women who DNA were successfully contacted and 50% of those attended a re-booked appointment this would increase the uptake to 84.2% for this cohort.

#### CHALLENGES AND UNCERTAINTIES

There was difficulty contacting women who did not attend their first timed appointment with less than 15% answering the phone. It is uncertain from this data what the uptake for this cohort would be with no phone call reminder before the fixed appointment.

#### SUSTAINABILITY

This intervention could be incorporated with other interventions involving direct contact with women through text messages, phone calls and letters as a way of offering support, providing information and reminding people to book or attend their appointments. It would be useful to check how much the reminder prior to the fixed appointment made a difference to attendance. This could be achieved by only carrying out follow up phone calls to those who DNA for three months and seeing if uptake is much lower than in the three months April-May 2022 when reminder phone calls had been made.

## Case study 4 East Cheshire & Stockport Breast Screening Programme: Text and phone reminders

## **Case Study**

#### AIM

To improve screening participation by reminding women to make an appointment to be screened using text messaging or phone calls.

#### CONTEXT

Prior to the pandemic, breast screening programmes sent a fixed appointment to women to attend breast screening with the opportunity to change the appointment if it was inconvenient. There is evidence that a fixed appointments approach results in increased participation in screening programmes, however it also results in a substantial number of empty appointment slots due to people who do not attend (DNA). Following the pandemic breast screening programmes switched to sending open appointment letters requiring women to call to make an appointment which typically results in fewer DNAs. This would maximise the use of appointments in the recovery phase of the screening programme following the pause in screening in March 2020 due to the pandemic. All women invited for screening were listed in a dummy or holding clinic and once they had phoned to make an appointment were transferred to a real clinic. This intervention aimed to send a reminder text message to women to prompt them to make an appointment.

#### METHODOLOGY

Dummy Breast screening clinics in Stockport and Macclesfield were monitored between 13th to 24th December following the first invitation sent to women to make an appointment to be screened. For women who had not made an appointment to be screened after a week their phone numbers were accessed. Before the clinics were closed and the final letter sent, (2 weeks after the first invitation) women who hadn't made an appointment were sent a text reminder or called if they had a landline number.

Text messages and calls were sent and made at different times of day to check if the response to them was better at certain times.

#### **FINDINGS**

Of the women who hadn't made an appointment to be screened a considerable proportion had missing phone numbers (31% to 68%). Responses to the text messages varied depending on the time of day they were sent. A 19% response of women calling to book an appointment within 24 hours of receiving a text was achieved when texts were sent at 18.15. The response rate was lower when texts were sent at other times of the day. After a further week there had been a 33% response to the text messages sent at 18.15.

Clinics	Not made an	Phone	No mobile	
	appointment	numbers	number able to	
		missing	receive texts	
Stockport 13-19th December	219	150 (68%)	34 (16%)	
Stockport 20-27th December	139	70 (50%)	11 (8%)	
Macclesfield 13-19th December	179	56 (31%)	12 (7%)	

Proportion of missing phone numbers for women who hadn't made an appointment to be screened.

There was a difficulty booking some women into the clinics because of lack of appointment availability, especially at the Stockport clinic site. Some women invited to the Stockport Clinic site are from higher deprivation areas and when offered appointments at the Macclesfield site said they were limited in how they could get to the clinic as they had no transport and were reluctant to attend. Based on this feedback the Stockport Clinic has added weekend sessions to increase numbers of available appointments.

Despite the overall good response to the text messages and phone call reminders, analysis of the proportion of women who booked but did not attend appointments remained static at between 4% and 5% (1 in 20 to 1 in 25 women). However, there will always be a proportion of women who forget, or are unable to attend appointments due to changes in circumstances.

#### STRENGTHS OF THIS APPROACH

Directly contacting women and reminding them to make a screening appointment is a known method of improving uptake. This approach maximises the available appointments and reduces the number of 2nd letters about not participating in screening that need to be sent. If the text message reminders will be an ongoing activity it will be important to ensure they are sent at the right time of day, which appears to be early evening.

#### CHALLENGES AND UNCERTAINTIES

This approach depends on being able to access accurate mobile phone or landline contact details of women invited for screening which is a manual process and so resource intensive. This could be rectified by changing the system so that when records are created for women about to be screened from the National Breast Screening Service database their phone numbers are automatically included in the new record. It is also important to ensure phone numbers are amended as soon as the admin team are aware of the changes.

Since the pandemic, in order to meet infection control requirements fewer women can be seen in any one clinic and this has inevitably reduced capacity. This means breast screening clinics may be full before the text message is due to be sent to women in the holding clinic and the breast screening programme is unable to achieve the full potential improved uptake.

#### SUSTAINABILITY

Sending text messages and phoning women does lead to an increase in booked appointments, however from this example it is unclear how this would impact on overall uptake. Streamlining the process of identifying phone numbers and sending text messages at the optimum time of day, combined with monitoring changes in uptake over a longer period is recommended to give a clearer view of the sustainability of this approach.

## Case study 5: Warrington, Halton, St Helens and Knowsley Breast Screening Programme: Working with PCNs

### **Case Study**

#### AIM

To support GP practices to contact women by text when they have been sent an invitation to book a breast screening appointment.

#### CONTEXT

Prior to the pandemic, breast screening programmes sent a fixed appointment to women to attend breast screening with the opportunity to change the appointment if it was inconvenient. There is evidence that a fixed appointments approach results in increased participation in screening programmes, however it also results in a substantial number of empty appointment slots due to people who do not attend (DNA). Following the pandemic breast screening programmes switched to sending open appointment letters requiring women to call to make an appointment which typically results in fewer DNAs. This would maximise the use of appointments in the recovery phase of the screening programme following the pause in screening in March 2020 due to the pandemic. All women invited for screening are listed in a dummy or holding clinic and once they make an appointment are transferred to a real clinic. This intervention aimed to support GPs to send text messages to remind women to make an appointment and identified women who hadn't attended screening in their practice who they also then prompted.

#### **METHODOLOGY**

The breast screening coordinator worked with Primary Care Network coordinators offering support to help improve breast screening uptake.

One GP surgery was supported by the screening coordinator to ensure they were messaging only eligible women who had been recently sent a routine invitation but had not yet made an appointment. A second GP surgery was supported to text women who had not attended their breast screening appointment. They were also provided with information and possible text content. This is the suggested wording for texts to women who have missed their appointment:

Your GP Practice supports breast screening. We understand that you have been unable to attend your breast screening appointment. Please contact your local breast screening service to re-arrange this. Find your local service here (links to website and contact phone number).

The breast screening programme requested that GPs sent the messages in small batches to ensure that the breast screening service wasn't inundated with calls all at one time which is frustrating for both the women and administrative teams answering the calls.

#### **FINDINGS**

Of the 4 PCNs (19 GP practices) in the catchment of the breast screening programme 2 PCN coordinators were keen to work with the breast screening service. Only 1 practice from each of the 2 PCNs took up the offer of support to text women to book or re-book their appointments.

#### STRENGTHS OF THIS APPROACH

Directly contacting people with further information and a reminder that they are eligible to participate in screening is an evidence-based approach to improving uptake. Sending reminders from a GP practice as has been implemented before for cervical screening reminders is an effective method of engaging with non-responders. Building good relationships between the breast screening programme, PCNs and GP practices supports the overall breast screening process. Often mobile vans are sited at GP practices and women direct questions to practice staff who don't always have information to hand. Strengthening communications helps with the flow of information to women and back to the breast screening unit. This work also supports the aim of PCNs, as part of their DES contract, to improve rates of early cancer diagnosis.

#### CHALLENGES AND UNCERTAINTIES

For this particular intervention no data has been gathered to show if the GPs sending text messages has improved breast screening uptake, for this practice.

This approach depends on GP practices having the capacity and capability to contact non responders and pass the information on to the screening coordinators. In order to contact people it will be important that practices have accurate mobile phone or landline contact details of people invited for screening.

Many GP Practices continue to experience heavy pressure on resources and service capacity. This pressure is likely to increase in the winter period, particularly if COVID-19-related illnesses increase alongside cases of seasonal flu. It is likely that some GP Practices will be keen to contact non responders but may not have the resources available to implement the activity.

#### SUSTAINABILITY

It is unclear as yet whether this will be a sustainable activity for breast cancer screening coordinators. Success of this intervention to make a difference to overall breast cancer screening uptake will rely on:

- the PCN DES specification continuing to require practices to make efforts to improve uptake and PCNs prioritising breast screening
- the practice capability and capacity to contact people
- the willingness of practices to work with the screening programmes and screening coordinators.

## Case study 6: Cheshire Bowel Cancer Screening Programme: Contacting non responders through a GP practice

**Case Study** 

#### AIM

To identify, and facilitate the contact of, bowel screening non-responders by GP practices to explore their reasons for non-participation, provide information, address concerns they have about participating and support individuals in completing their test kit should they wish to do so.

#### CONTEXT

Inviting people for bowel cancer screening is carried out by one of five bowel screening hubs across the country who send out information, screening test kits (for people to complete at home) and receive the test kits for processing in a pathology laboratory. People with a positive screening result are booked into a local bowel cancer screening centre for an appointment with a specialist screening practitioner and further diagnostic tests. Neither the GP practice nor the bowel cancer screening centre (where the screening coordinator is based) are involved with this part of the screening pathway. The bowel screening hub notify the GP practice of the screening test result, either positive, negative or did not respond, around 6 months after the invitation is sent. As such the only way to identify non responders is either through the hub or GP practices once the screening test result has been recorded. Each GP belongs to a Primary Care Network (PCN) of practices. Each PCN has a contract to provide Direct Enhanced Services (DES) to its population and one element of the service specification around early cancer diagnosis is to improve local uptake of National Cancer Screening Programmes.

#### METHODOLOGY

The Cheshire Bowel Cancer Screening Programme covers around 92 practices of which 20 were targeted and offered support from the Bowel Cancer Screening Coordinator. These 20 practices were selected based on overall screening uptake, total number of non-responders and Index of Multiple Deprivation (IMD) score. Practices were contacted and support offered from the Bowel Cancer Screening Coordinator.

One practice, agreed to work with the screening coordinator to contact non responders. Letter and questionnaire content was developed by the screening programme and agreed with the Regional Screening Hub in Rugby and the Mid Cheshire Hospitals NHS Foundation Trust Communications Team. The letter and questionnaire aimed to:

- Act as a screening reminder (in case a person simply forgot to complete their screening kit).
- Provide key information on bowel screening.

- Signpost the individual towards key contacts (such as their GP Practice and the Regional Screening Hub) in order for any questions or concerns to be answered, or any barriers overcome.
- Detail how the individual can take part in screening should they now wish to.
- Seek to discover reasons for non-participation.

Between October 2021 and April 2022, Westminster Surgery sent a covering letter, questionnaire, and a prepaid envelope to all non-responders from the 2021 calendar year.

In June 2022 the Bowel Cancer Screening Coordinator received the list of 82 NHS numbers of non-responders who had been sent the letter and questionnaire. The data was checked on the Bowel Cancer Screening System to see if there had been further participation in screening in response to the reminder.

#### FINDINGS

Before the pandemic in 2019, Westminster GP surgery based in Ellesmere Port, had an uptake of 51.5%, much lower compared to the overall uptake of the West Cheshire CCG of 68.3%. The IMD score for the practice is in the 9<sup>th</sup> decile for England which means it serves populations who are between 10 -20% most deprived in the country. The practice is relatively small with 136 people eligible for screening in 2019 of which 70 participated in the programme (51.57%). In 2021 there were 247 eligible people invited for screening of which 155 participated without any further reminders. Non responder letters and questionnaires were sent to 92 people of whom 11 subsequently completed a FIT kit. This is an additional 4.4% of the eligible cohort who took up the offer of screening in response to the reminder.

	Invited	Participation following invite (% uptake)	Participation after reminder
2019	136	70 (51.5%)	N/A
2021	247	155 (62.8%)	166 (67.2%)

Only one person returned the questionnaire about why they didn't want to participate in the bowel screening programme and had no intention to do so in the future. The indicated reasons were:

- A dislike of the bowel screening process.
- A fear of being diagnosed with cancer.
- I am healthy and feel fine, therefore I'm not currently worried about bowel cancer.
- Nobody in my family has ever had bowel cancer, therefore I feel I'm low risk.

#### STRENGTHS OF THIS APPROACH

Directly contacting people and with further information and a reminder that they are eligible to participate in screening is an evidence-based approach to improving uptake. Sending reminders from a GP practice as has been implemented before for cervical screening reminders is an effective method of engaging with non-responders. Due to the way the Bowel Cancer Screening Programme is organised from a central hub this approach has largely not been implemented through primary care. Having the PCN DES in place helps encourage practices to engage in improving screening uptake even though they are not involved in the screening programme directly.

#### CHALLENGES AND UNCERTAINTIES

This approach depends on GP practices having the capacity and capability to contact non responders and pass the information on to the screening coordinators. In order to contact people it will be important that practices have accurate mobile phone or landline contact details of people invited for screening.

Some practices are opting to focus on cervical or breast screening uptake rather than bowel screening to meet their DES requirements. It is unclear why this is the case but possibly because there is already a good relationship with people carrying out screening. Practice nurses carry out cervical sampling at GP surgeries and breast screening staff often visit practices prior to their women being invited for screening in a van which may well be sited in the practice car park. In contrast there is very little contact between bowel cancer screening hubs, and primary care staff.

Many GP Practices continue to experience heavy pressure on resources and service capacity. This pressure is likely to increase in the winter period, particularly if COVID-19-related illnesses increase alongside cases of seasonal flu. It is likely that some GP Practices will be keen to contact non responders but may not have the resources available to implement the activity.

#### SUSTAINABILITY

It is unclear as yet whether this will be a sustainable activity for bowel cancer screening coordinators. The outcomes from this one practice have shown that an improvement in uptake is possible by sending a reminder letter with information and signposting to non-responders. It is unclear if this approach would show similar (4.4%) improvements in participation if it was implemented in all 20 targeted practices in Cheshire. Success of this intervention to make a difference to overall bowel cancer screening uptake will rely on:

- the PCN DES specification continuing to require practices to make efforts to improve uptake
- the practice capability and capacity to identify and contact people
- the willingness of practices to work with the screening programmes and screening coordinators.

It may be more appropriate to have screening coordinators employed by PCNs so they can directly contact non responders themselves and be an additional resource for PCNs to meet their DES specification requirements.

# Case study 7: Contacting non responders through a GP practice

**Case Study** 

#### AIM

To identify, and facilitate the contact of, bowel screening non-responders by GP practices to explore their reasons for non-participation, provide information, address concerns they have about participating and support individuals in completing their test kit should they wish to do so.

#### CONTEXT

Inviting people aged 60 to 75 for bowel cancer screening is carried out by one of five bowel screening hubs across the country who send out information, screening test kits (for people to complete at home) and receive the test kits for processing in a pathology laboratory. People with a positive screening result are booked into a local bowel cancer screening centre for an appointment with a specialist screening practitioner and further diagnostic tests. Neither the GP practice nor the bowel cancer screening centre (where the screening coordinator is based) are involved with this part of the screening pathway. The bowel screening hub notify the GP practice of the screening test result, either positive, negative or did not respond, around 6 months after the invitation is sent. The only way to identify non responders is either through the hub or GP practices once the screening test result has been recorded. Each GP surgery belongs to a Primary Care Network (PCN) of practices. Each PCN has a contract to provide Direct Enhanced Services (DES) to its population and one element of the service specification around early cancer diagnosis is to improve local uptake of National Cancer Screening Programmes.

#### METHODOLOGY

The bowel cancer screening coordinator identified 20% of GP practices covered by the screening programme with the lowest uptake as reported in the 2019 calendar year uptake data (i.e., a full year pre-pandemic). PCN cancer leads for these practices were approached to offer support in improving uptake. Two of 10 PCN cancer leads were keen to work with the screening coordinators to improve bowel screening uptake, however only one practice within one PCN ultimately agreed to the project.

People who had not responded to the offer of bowel cancer screening in the past 6 months were identified and their contact details accessed. Contact with non-responders involved:

- Texting people with a mobile phone number with information on how to be screened and who to contact with queries this was followed up with a letter
- Sending a letter to people with no mobile phone which was followed up with a landline phone call if available

Content for the text message, a script for a guided conversation and letter wording was developed that included the key messages the screening coordinators wished to convey. This was agreed

by the PCN cancer lead. Responses to the different types of contact were recorded in an excel spreadsheet in addition to the age of the individual, the completion of a bowel screening test kit and the result.

#### FINDINGS

A total of 310 people at Aintree Westmoreland Practice were contacted with a text message, letter, or phone call to remind them about their eligibility for bowel cancer screening between February and June 2022.

The table below shows the age range, method of 1<sup>st</sup> and 2<sup>nd</sup> contact, number of people contacted, kits returned and their result. Overall of the 310 people contacted, 20 responded by completing a test kit. None of the test results from the kits completed were abnormal.

Of the people who had received their first ever invite for bowel cancer screening at age 60 but hadn't responded and were then sent a reminder text message, 9.8% (n=7) responded and completed a test kit. This was the highest response to contact of any age group and method of contact. Around 5.8% (n=3) of those aged 62-63 who received only a text message responded, whilst none of the 79 people responded who were aged 64 to 66. For older age groups aged 67-69, 2.7% (n=2) responded and for those aged 70-75, 1.1% (n=1) responded by completing a test kit. For those that did not respond to a text and were then sent a letter around 4.3% (n=3) of people aged 60-61, 4.1%(n=2) of those aged 62-63, and 3.2% (n-2) aged 64-66 responded. There was no response from people of any age group to being sent only a letter.

Age	1st and 2nd methods of contact	People contacted (No) of total	Kits returned /abnormal result	% DNAs who responded
60-61 (n=77)	1st Text	71	7/0	9.8%
	1st Text 2nd letter	64	3/0	4.3%
	1st Letter	6	0/0	0
	1st Letter 2nd phone call	6	0/0	0
62-63 (n=66)	1st Text	51	3/0	5.8%
	1st Text 2nd letter	48	2/0	4.1%
	1st Letter (no phone number)	15	0/0	0
64-66 (n=79)	1st Text	79	0/0	0
	1st Text 2nd letter	62	2/0	3.2%
	1st Letter (no phone number)	13	0/0	0
67-69 (n=88)	1st Text	74	2/0	2.7%
	1st Text 2nd letter	70	0/0	0
	1st Letter (no phone number)	15	0/0	0
70-75 (n=116)	1st Text	88	1/0	1.1%
	1st Letter	28	0/0	0
Total (n=310)			20	6.5%

#### Outcomes of directly contacting bowel screening non responders via a GP practice

This approach seems to work best for those who haven't previously been invited for screening as there was 14.1% response of non-responders in the 60-to-61-year age group. There is a trend for those in older age groups being less likely to respond to text messages/letters (1.1%)

in those aged 70 to 75). It is unclear why this is the case although it may be partly due to other competing health concerns as people age.

#### STRENGTHS OF THIS APPROACH

Directly contacting people with further information and a reminder that they are eligible to participate in screening is an evidence-based approach to improving uptake. Sending reminders from a GP practice as has been implemented before for cervical screening reminders is an effective method of engaging with non-responders. Due to the way the Bowel Cancer Screening Programme is organised from a central hub this approach has largely not been implemented through primary care. Having the PCN DES in place helps encourage practices to engage in improving screening uptake even though they are not involved in the screening programme directly.

#### CHALLENGES AND UNCERTAINTIES

This approach depends on GP practices having the capacity and capability to contact non responders and pass the information on to the screening coordinators. In order to contact people it will be important that practices have accurate home addresses, mobile phone, and landline contact details of people eligible for screening

Some practices are opting to focus on cervical or breast screening uptake rather than bowel screening to meet their DES requirements. It is unclear why this is the case but possibly because there is already a good relationship with people carrying out screening. Practice nurses carry out cervical sampling at GP surgeries and breast screening staff often visit practices prior to their women being invited for screening in a van which may well be sited in the practice car park. In contrast there is very little contact between bowel cancer screening hubs, and primary care staff.

Many GP Practices continue to experience heavy pressure on resources and service capacity. This pressure is likely to increase in the winter period, particularly if COVID-19-related illnesses increase alongside cases of seasonal flu. It is likely that some GP Practices will be keen to contact non responders but may not have the resources available to implement the activity.

#### SUSTAINABILITY

It is unclear as yet whether this will be a sustainable activity for bowel cancer screening coordinators. The outcomes from this one practice have shown that text message reminders sent to people who have not responded to their first ever invitation for screening results in the greatest improvement in uptake. Success of this intervention to make a difference to overall bowel cancer screening uptake will rely on:

- the PCN DES specification continuing to require practices to make efforts to improve uptake
- the practice capability and capacity to identify and contact people
- the willingness of practices to work with the screening programmes and screening coordinators.

It may be more appropriate to have screening coordinators employed by PCNs so that they can directly contact non responders themselves and be an additional resource for PCNs to meet their DES specification requirements.

Case Study 8: Crewe Bowel Cancer Screening Programme: Community engagement to increase men's awareness of bowel cancer screening

**Case Study** 

#### AIM

To raise men's awareness of bowel cancer screening.

#### CONTEXT

Men are disproportionately affected by bowel cancer, both in terms of diagnosis and mortality rates. Cancer Research UK estimate that 1 in 15 men will be diagnosed with bowel cancer during their lifetimes, compared to 1 in 18 women. Despite the higher diagnosis and mortality rates of bowel cancer in men, women are more likely to participate in screening. Public awareness is an important element in improving uptake to increase self-mobilisation and action. Awareness raising requires strategies of effective communication to reach the desired outcome, strategic planning to reach a target audience and for communication of a specific message tailored to that target group.

#### ACTIVITY

The Crewe Bowel Cancer Screening Programme (BCSP) coordinator targeted organisations such as sports clubs, teams and leagues, gyms, and charities where male membership was high. This included:

- 24 Golf Clubs
- 6 Football Clubs
- 13 Tennis Clubs
- 10 Cricket Clubs
- 39 Bowling Clubs / Leagues
- 5 Charities
- 30 Gyms

Examples of these organisations include Crewe Alexandra Football club with over 1000 season ticket holders who are 60 years old or over, 90% of which are male and the Mid Cheshire Bowling league with 56 teams and 35 clubs with over 1000 members of which 75% are over 60 years of age, and 80% are male.

The screening coordinator sent an initial letter about bowel cancer screening and how best to engage with their members in raising awareness. A range of digital and physical resources were made available, including:

- informative leaflets and guides
- posters
- social media (social media channels to share information digitally)
- websites (webpages of the groups contacted, to share information digitally)
- key weblinks as a signpost for people
- videos instruction / informative videos
- a press release that groups and organisations can share via a newsletter, social media post or via their website.
- credit card sized 'wallet cards', from Cancer Research UK and Bowel Cancer UK, containing key information about bowel cancer screening

#### EVALUATION

A log of all the organisations contacted and those who responded positively was kept along with verbal feedback about the approach and response to the awareness raising activity.

#### OUTCOMES

In total, 127 organisations were contacted, of which 51 positively responded and have since actively supported the screening coordinators health promotion activities by completing positive, meaningful actions including:

- Crewe Alexandra Football club agreed to place 30 bowel cancer screening posters around their stadium, in easy view of supporters on matchdays.
- Each club of the Mid Cheshire Bowling League received four posters, as well as a selection of leaflets, guides and wallet-sized cards to leave in their clubhouse for their members and visitors to view, read and take home.
- Six golf clubs across Cheshire actively supported bowel cancer screening health promotion activities by placing posters on public view around their clubs, in addition to leaving bowel cancer screening leaflets and guides in their members bar area.

Feedback received, verbally and via feedback forms, was very positive. It was clear that many of the organisations that chose to engage with the health promotion activities have employees that had either been personally diagnosed with bowel cancer or knew somebody that had.

#### STRENGTHS OF THIS APPROACH

People's awareness of a health condition and screening options is an important element in the decision-making process as to whether to participate in a screening programme. Targeting particular organisations whose membership includes a high proportion of the target population (in this case men) is important in disseminating the key messages about participating in bowel cancer screening.

#### CHALLENGES AND UNCERTAINTIES

Only 40% of organisations approached responded with active support to disseminate the health promotion message. Reasons for not engaging include:

- Lack of awareness of the threat that bowel cancer poses
- Some organisations are still running on skeleton staff due to the pandemic or have had a lot of staff leave in 2021

• Organisations such as individual leisure centres, said that they need to receive authorisation from the senior management at their umbrella organisation before they are allowed to endorse any information

Although an important activity, it is not clear whether exposure to the health promotion materials led to people taking up their invitation to be screened.

#### SUSTAINABILITY

Raising awareness of cancer screening is important but it isn't clear whether this activity will have made a difference in improving screening participation. Without evidence that these awareness raising activities increase screening participation, it may be best for this type of community engagement to comprise a relatively minor part of a screening coordinator's role.

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