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School
Of
Health And
Related Research.

Evaluation of the Cancer Wise Leeds Project Interim Report



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Prepared for: Yorkshire Cancer Research

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Executive summary

Chapter one provides a brief background and introduction to the evaluation.

Chapter two details the bespoke quantitative data we have sought to evaluate the programme and what has been received. It goes on to present our “data ask” going forward.

Chapter three outlines findings from the qualitative workshops. Since the initial report in July 2020, we have carried out a further six workshops making a total of 11 to date. These recent workshops have collected qualitative data focused on the coordinators’ role in the development of new initiatives such as the weekend cervical screening hub, and how the Cancer Wise Leeds Cancer Screening and Awareness Coordinators’ (CS&AC) role has changed over time. Two workshops explored the common barriers to screening from the perspective of colleagues working in the Leeds Cancer Awareness project and members of the public. A workshop with senior staff identified the strategic direction of the programme, where attendees noted how the emphasis of the programme had shifted over time, for example with less emphasis on developing community partnerships and the role CS&ACs played in identifying education and training. The final workshop explored the timings and focus of programme activities now and in the future, with a discussion on specific plans to increase participation in breast, cervical and bowel cancer screening.

Chapter four presents the trends in the cancer screening programmes’ performances against comparable areas and, separately, compares Primary Care Networks (PCNs) within Leeds.

In **Chapter five**, we present an update to the economic modelling analysis. The planned interim economic analysis was not feasible due to disruption from COVID-19, so instead we present results from a minimum effect analysis, in which we calculate the minimal increase in coverage that is required as a consequence of the CS&AC programme, for the programme to be cost-effective given the budget that has been spent on it. For this analysis we focus only on cervical and bowel cancer screening, as little CS&AC time has been spent on breast cancer screening so far.

Conclusions

1. Qualitative data indicate the benefits of CS&ACs in terms of providing an **increased understanding of the local population**. In particular, our findings highlight the positive effects of CS&ACs carrying out in-depth scrutiny of sub-population data and between-group variance, in order to explore explanations for non-attendance and variations between population groups. This work has been a key element of the role and was not previously possible before introduction of the programme. By better understanding local data, the CS&ACs have been able to recommend ways to better enable and facilitate people to take up screening. The data highlight that each Primary Care Network operates very differently, so a **context driven** approach is required to plan and deliver interventions at a local population level.
2. Qualitative data emphasise the importance of having people **embedded in primary care**, who are perceived to be and are in actuality part of the team. The CS&ACs are seen by many to have the role of experts in cancer screening, and are increasingly well recognised for what they do locally. They are also perceived to have a valuable role in **providing support** on cancer screening to PCNs and individual practices.
3. Positive effects on cancer screening rates are perceived to have occurred as a result of **informal and formal sharing of information and expertise**. Informal routes include the cascading of latest research and up to date local data, and more formal routes have included supporting Cancer Champions by developing and delivering training in collaboration with Cancer Research UK, and cascading and sharing resources.
4. Qualitative data suggest that the CS&ACs have acted as **agents for change**, by taking the lead on local innovations to service delivery (such as out of hours clinics), and being a proactive voice arguing for how things can be done differently. Their role in changing ways of working within and across PCNs has the potential to lead to future cost savings associated with sharing resources in Leeds.
5. The context of the Covid-19 pandemic has been a catalyst for greater **collaborative working** between individual practices and primary care networks, and the CS&ACs have been able to capitalise on these opportunities for sharing innovation and learning. An example of where potential impact may result from their role in

increasing collaboration, has been working with Extended Access to increase the availability of appointments.

Results of the economic analysis indicate that over its 3.5 year duration the CS&AC programme needs to improve coverage of **cervical cancer screening by a minimum of 6.3% (an additional 9724 screening participations)** and **bowel cancer screening by a minimum 4.4% (an additional 2434 screening participations)** to ensure that the programme achieves a cost effectiveness of £20,000 per quality adjusted life year (QALY) gained. Agreed revised target KPIs for cervical screening coverage are aiming for a 3% increase, which is insufficient to ensure that the cervical part of the CS&AC programme will be cost-effective at this threshold. Target bowel cancer screening KPIs are 5%, which is sufficient to ensure that the bowel cancer part of the CS&AC programme is cost-effective, assuming that increases are over and above those expected throughout England due to the change to FIT screening.

Table summarising current (revised) programme KPIs and recommended minimum KPI targets

	Cervical Cancer	Bowel Cancer
Programme KPI: Actual Numbers Additional Participations	4608	2778
Programme KPI: % Increase in Coverage	3.0%	5.0%
Recommended Minimum KPI Targets: Actual Numbers Additional Participations	9724	2434
Recommended Minimum KPI Targets: % Increase in Coverage	6.3%	4.4%

Recommendations

1. An area where qualitative data indicate improvements could be made relates to **staffing**, and includes the introduction of a more formalised induction process for new CS&ACs, together with having a timely training package in place including instruction on SystemOne and data analysis methods. Staff turnover and staffing generally has been a considerable challenge exacerbated by the Covid-19 pandemic, improved induction and ongoing support may have a key role in retention. The obstacle of non-

NHS pensions, issues around secondment and a lack of clarity regarding the CS&AC role have also contributed to staffing difficulties.

2. It is suggested that there could be enhanced consistency in the **support** provided to individual CS&ACs, which was reported to be varied. There appears to have been considerable leaning on the existing skills and areas of interest of staff.
3. While there has been a growing recognition of the role of the CS&ACs, there is still work to be done in some quarters to ensure an awareness and **appreciation of the role** from other stakeholders including within PCNs.
4. The value of moving away from a focus on individual practices to more **PCN-wide** activities is recommended to provide opportunities for applications for future funding screening initiatives.
5. There seems to be potential for CS&AC to be a greater embedded part of Extended Access working on **population health management**.
6. The inclusion of the **voluntary sector** in the development of new initiatives is important, so they are able to inform the communities they work in. This seems to be a key area for future further development.
7. It is recommended that **screening coverage KPI targets** are set that are a minimum of 4.4% higher for bowel cancer (an additional 2434 screening participations) and 6.3% higher for cervical cancer (an additional 9724 screening participations), than coverage would be expected to be according to prior trends or national comparisons. Such targets would be required to ensure that the programme will be cost-effective based on current NICE cost effectiveness criteria.

Table of Definitions

Term	Definition within this report
Coverage (rate)	The proportion of the eligible population who were screened adequately at least once within the defined screening target period. Coverage represents the ability of a screening programme to reach its target population over its target period. Coverage is a “lagged” measure as it incorporates the performance of the screening programme at earlier times in addition to the indicated period.
Participation	Generally the non-technical dictionary definition is intended. Where specifically referring, the appropriate screening of eligible individuals at any time.
Reporting period	The specified time period over which activities should be included.
“Screened adequately”	Screened successfully, produced a valid result.
Uptake (rate)	The proportion of (eligible) persons invited for screening in the reporting period who were screened adequately within 6 months of invitation. Uptake represents a measure of short-term (6 month) invitee engagement with the screening programme. It incorporates only activity within the indicated period thus does not suffer from the lag associated with coverage. However, uptake does not include participation of those who participate in screening more than six months after being invited.

1. Background

The School of Health and Related Research (SchARR) is undertaking an evaluation of the Cancer Screening and Awareness Programme (Cancer Wise Leeds) on behalf of Yorkshire Cancer Research. The programme aims to increase cancer screening coverage in Leeds across the national breast, cervical and bowel cancer screening programmes. The evaluation period overall covers work within the programme s from October 2019 to September 2022. The purpose of the evaluation overall is to:

- Determine the effectiveness of the programme's interventions against the programme outcomes
- Assess the cost effectiveness of the programme
- Offer any recommendations that may subsequently improve the programme's delivery in the future and improve the programme's costs effectiveness.

This interim report was requested by the funder in order to provide a mid-point overview of progress of the evaluation and highlight any learning, which could be taken forward.

In order to evaluate this programme, SchARR are undertaking an approach with a strong emphasis on stakeholder engagement and continuous learning cycles running throughout. We are drawing on a theory of change approach, working with stakeholders to develop a shared understanding of the system, goals, options for change and to inform priorities for action. Our evaluation is taking a systems perspective, exploring in depth the outcomes for and views and experiences of the local population, together with outcomes relating to the workforce, and the system as a whole.

The evaluation overall aims to use cancer specific models for bowel, breast and cervical cancer to bring together evidence throughout the cancer pathway. This will enable predictions of clinical impact, for example cancer incidence, stage at diagnosis distribution, longer term patient outcomes including cancer mortality and quality of life, costs, resources and cost effectiveness. The evaluation also seeks to understand the pathway of change between interventions and impact, drawing on different forms of evidence to explore understandings and hypotheses regarding the way the Cancer Screening and Awareness Coordinators (CS&AC) intervention is intended to operate in order to achieve optimal outcomes.

The Cancer Screening and Awareness Programme (Cancer Wise Leeds) has been affected by the unprecedented global Covid 19 crisis from March 2020 to the present time, and this has had inevitable impacts on the programme and its evaluation. This report therefore should be read in the light of this pandemic which led to the CWL programme team conducting a gap analysis to review the impact of the pandemic on programme targets and led to the proposal of new KPIs and a revised programme budget. This was explored during the data collection in particular during the qualitative workshops.

This interim report describes the activities and progress for work between July 2020 and October 2021. It includes details of how the programme and the evaluation have been modified to take account of these changed circumstances.

The key activities of work undertaken during this time period encompass the following three interlinking strands: (1) examination of information from the programme metrics; (2) workshops with stakeholders; (3) analysis of economic evidence.

Work completed within these different strands of the work package is detailed in the following sections.

2. Evaluation data requests

In February 2020 we agreed a data sharing agreement with Leeds City Council for anonymised, aggregate patient data. The data requested were counts of individuals in groups defined by:

- period end / epoch (the time point for which the measure is valid) [monthly from March 2016 onward]
- primary care network [NHS Leeds CCG PCNs]
- age (single years) [20 - 80 (inclusive)]
- sex (as recorded in GP record)
- ethnic category (as recorded in GP record)
- Overall Index of Deprivation (2019) decile of LSOA of place of residence (based on postcode in GP record)
- Gypsy, Roma or Traveller indicator
- learning disabilities indicator
- measure:
 - Eligible for Bowel Cancer Screening in last 2 years
 - Eligible for Breast Cancer Screening in last 3 years
 - Eligible for Cervical Cancer Screening in last 3 years
 - Eligible for Cervical Cancer Screening in last 5 years
 - Attended Bowel Cancer Screening in last 2 years
 - Attended Breast Cancer Screening in last 3 years
 - Attended Cervical Cancer Screening in last 3 years
 - Attended Cervical Cancer Screening in last 5 years

Leeds City Council was unable to provide this data itself but made approaches, in February 2021, to NHS Leeds Clinical Commissioning Group (CCG) to provide this information. We worked with NHS Leeds CCG directly and received some data from NHS Leeds CCG in May 2021.

Unfortunately, NHS Leeds CCG was unable to reproduce the exclusion criteria for the “Eligible for...” measures, so patients excluded in national metrics were included in the NHS Leeds CCG

provided data. Individuals may withdraw from screening programmes and/or be ineligible (e.g. those having undergone bilateral mastectomy or total hysterectomy). This means coverage estimates derived from the NHS Leeds CCG provided data differ from nationally published coverage statistics.

Moreover, NHS Leeds CCG is only able to extract this information from live GP information systems for practices (operating either SystmOne or EMIS) in NHS Leeds CCG. Patients who are no longer registered with an NHS Leeds CCG GP practice (e.g. have moved or died) are not recorded in the data available to NHS Leeds CCG. Thus it is not possible for NHS Leeds CCG to provide historic coverage rates from this data.

Some measures calculated from the NHS Leeds CCG provided data diverge significantly from figures published by both NHS Digital and PHE (see 1). The issues highlighted in the previous two paragraphs (imprecise eligibility criteria and data only available for the population as at the date of data extract) are unlikely to fully account for all of these differences but we have been unable to ascertain further reason for these discrepancies with NHS Leeds CCG.

Table 1: Comparison of measures by source.

Measure	Element	Period	Leeds CCG provided data (April 2021)	PHE Published ¹	NHS Digital Published ²
Persons, 50-70, screened for breast cancer in last 36 months (3 year coverage)	numerator	as at April 2021	58,960	63,968	Comparable figures not available
Persons, 50-70, screened for breast cancer in last 36 months (3 year coverage)	denominator	as at April 2021	95,845	95,766	Comparable figures not available
Persons, 50-70, screened for breast cancer in last 36 months (3 year coverage)	%	as at April 2021	61.5%	66.8%	Comparable figures not available
Persons, 60-74, screened for bowel cancer in last 30 months (2.5 year coverage)	numerator	as at April 2021	95,892	79,349	Comparable figures not available
Persons, 60-74, screened for bowel cancer in last 30 months (2.5 year coverage)	denominator	as at April 2021	115,369	115,083	Comparable figures not available
Persons, 60-74, screened for bowel cancer in last 30 months (2.5 year coverage)	%	as at April 2021	83.1%	68.9%	Comparable figures not available

¹ Office for Health Improvement and Disparities. Public health profiles. 2022 <https://fingertips.phe.org.uk/profile/cancerservices/data> © Crown copyright 2022.

² NHS Digital data. Cervical Screening (Quarterly). 2022 <https://digital.nhs.uk/data-and-information/publications/statistical/cervical-screening-programme> © 2022 NHS Digital.

Measure	Element	Period	Leeds CCG provided data (April 2021)	PHE Published ¹	NHS Digital Published ²
Persons, 25-49, attending cervical screening within target period (3.5 year coverage)	numerator	as at April 2021	151,763	108,552	108,314
Persons, 25-49, attending cervical screening within target period (3.5 year coverage)	denominator	as at April 2021	158,501	157,675	157,632
Persons, 25-49, attending cervical screening within target period (3.5 year coverage)	%	as at April 2021	95.7%	68.8%	68.7%
Persons, 50-64, attending cervical screening within target period (5.5 year coverage)	numerator	as at April 2021	46,843	50,299	50,190
Persons, 50-64, attending cervical screening within target period (5.5 year coverage)	denominator	as at April 2021	74,185	66,612	66,503
Persons, 50-64, attending cervical screening within target period (5.5 year coverage)	%	as at April 2021	63.1%	75.5%	75.5%

Separately, NHS Leeds CCG have supplied the CWL programme with data on screening coverage (to inform CWL's KPIs) but this data slightly diverges from available published figures. NHS Leeds CCG have confirmed this divergence is due to the national reporting system and outside of their control.

In the absence of reliable figures we have continued to use data published by national bodies, NHS Digital and Public Health England, in this report.

Data desired to inform the final evaluation report

The problems in acquiring data have led us to develop a narrower data specification of data items desired to inform the final evaluation report. Ideally, we would like monthly counts (from March 2016 onward) of the:

- eligible population
- invited population
- screened population

- those with positive result at screening
- those who take-up follow-up after a positive result

The above disaggregated by:

- age
- sex
- deprivation (IMD)
- ethnicity
- PCN
- previous screening status
 - new invitee
 - previous responder
 - previous non-responder

We appreciate that this may not be possible to achieve in full but we would like to understand what is achievable with the CWL programme team and NHS Leeds CCG.

3. Workshops with stakeholders

Understanding implementation and pathways to effects

Since the last report at the end of July 2020 we have carried out a further six workshops as part of work package 2. These workshops have continued the detailed qualitative exploration and evaluation of the programme, building on the five workshops completed as part of work package 1.

The workshops completed to date within WP2 (numbered to follow on from workshops 1-5 in WP1) are as below:

Workshop 6 - November 2020 Workshop with staff involved in development of a weekend screening service.

Workshop 7 - January 2021 Workshop with CS&ACs exploring their developing role.

Workshop 8 - April 2021 Workshop with colleagues from Leeds Cancer Awareness Project exploring barriers to screening.

Workshop 9 - May 2021 Workshop with members of the public exploring screening participation and services in Leeds.

Workshop 10 - June 2021 Workshop with senior staff exploring the developing programme strategy.

Workshop 11 – November 2021 Workshop with CS&ACs exploring the elements of the intervention, and where the time and focus of activities has been to date and will be in the future.

Understanding the developing role of the Cancer Screening and Awareness Coordinators

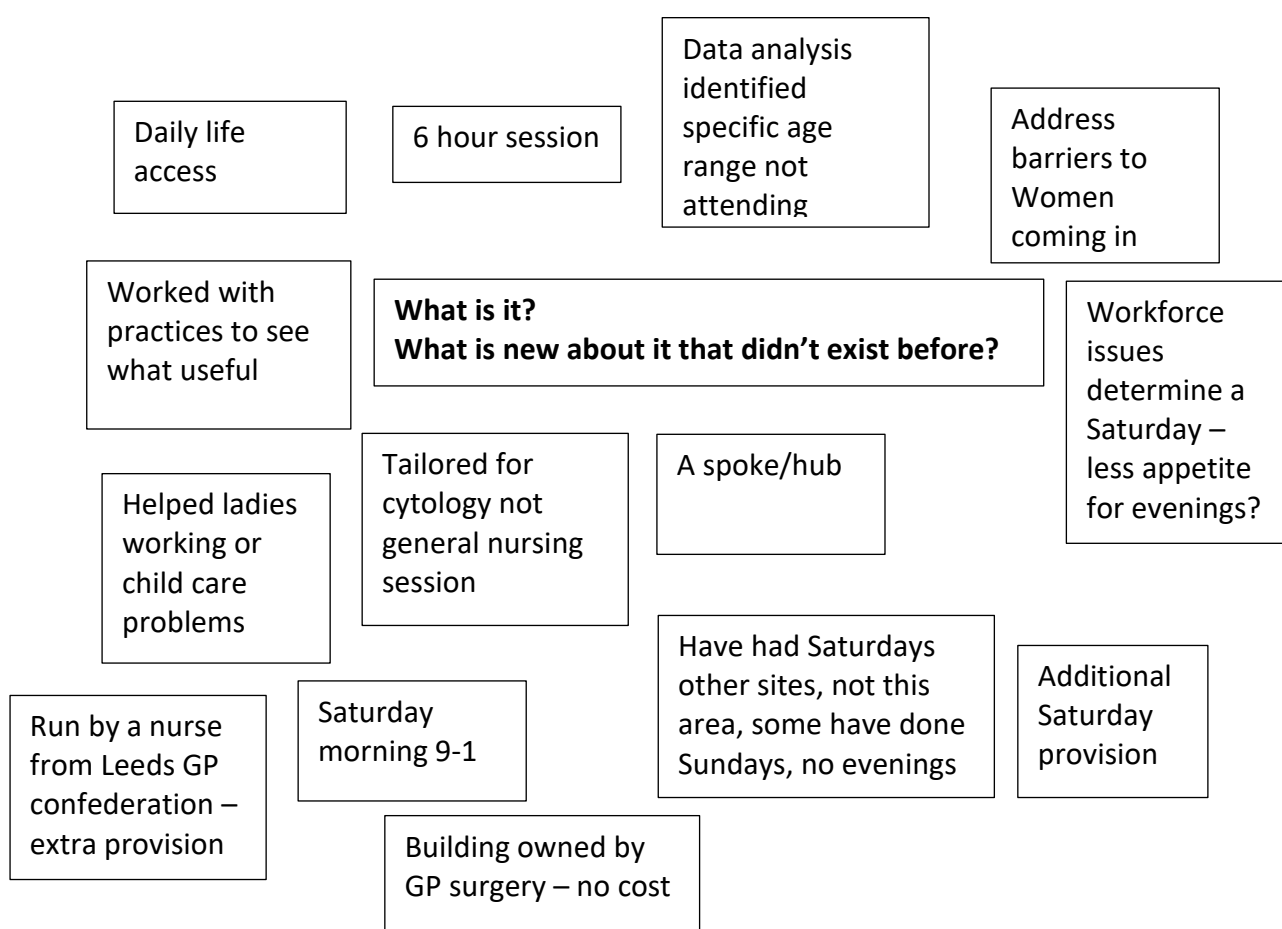
Workshop 6 - November 2020

In workshop 6 we examined an example of an initiative that had been led by the CS&ACs at one PCN. This initiative (a weekend cervical screening clinic/hub) provides an interesting case study illustrating the developing role of the CS&ACs, but also offers insights into the emerging effects of the CS&ACs more widely. The workshop was attended by six members of staff from the programme including two CS&ACs, together with operations and communications

managers from the Council, PCN and GP confederation. See Figure 1-6 for the jamboards used during the workshop to note discussion points.

At the beginning of the workshop we explored what the elements of the initiative are and how exactly it differed from existing provision.

Figure 1. Jamboard from discussion 1



The weekend cytology hub

The service operates on a Saturday morning between 9 am and 1pm. It is run by a cytology nurse working for the Leeds GP Confederation. At the time of the workshop the CCG had a contract with the GP Confederation to provide this for all General Practices in Leeds, but it was planned that in subsequent years the money would go direct to PCNs to decide whether to provide the service themselves or continue to commission via the GP Confederation.

Other sites within the PCN already had an established Saturday nurse session with some cytology alongside wound dressings etc. which had been operating for several years. But this

was described as the first weekend session that is specifically tailored at cytology. Participants were not aware of any evening services, which they attributed to nursing staff preferring to work on a Saturday as they could have a preferable longer six hour shift.

The role of the CS&ACs in establishment of the initiative

The introduction of the clinic had been the result of work that had been carried out by one of the previous CS&ACs as part of the role. Clinical systems had been scrutinised for information regarding characteristics of people with a cervix who were not attending for cervical screening. The data were broken down into 10-year age groups, and provided information on those who had had a previous smear recorded, ethnicity, and postcode. The CS&AC had telephoned a sample of non-attenders to explore why they had not engaged with the programme. While some individuals reported that they had simply forgotten, issues around daily life (due to work, childcare etc.) were reported to be obstacles for a specific age range of working age people who were not attending. This had indicated that available appointments for cervical screening were often not convenient. As an additional benefit, during these phone calls many cervical screening appointments were perceived as being booked (specific data was not available).

Participants attributed the personalisation and the ability of the CS&ACs to drill down into absolute population data, at PCN level and even down to street names as a key element of establishing the need for the additional screening session option. The general view was that “it would never have happened had the CS&AC not been in post”, as people in practice/at a PCN level would not have had time to do the research and the in-depth scrutiny of sub-population data. It was highlighted that also the PCN agenda is substantial, so there would not be time to explore specific small pieces of work. One participant commented that while cancer screening is a key priority in GP practices, people tend to “just put up the posters, try and get people to come in but don’t dig deeper”.

Figure 2. Jamboard from discussion 2



Levers for introduction and potential for rollout

Participants recalled that the decision to introduce the initiative had been supported by having confidence in the data. As one person put it “as we knew it had been drilled down from our data, the CS&ACs understood the local population and interpreted the data....(that) is where the confidence has come from”. It was outlined how a “clinical hook was there”, with the local relevance of the data acting as a key incentive for people having decision-making roles to engage with the proposal. These decision-makers were people who “were

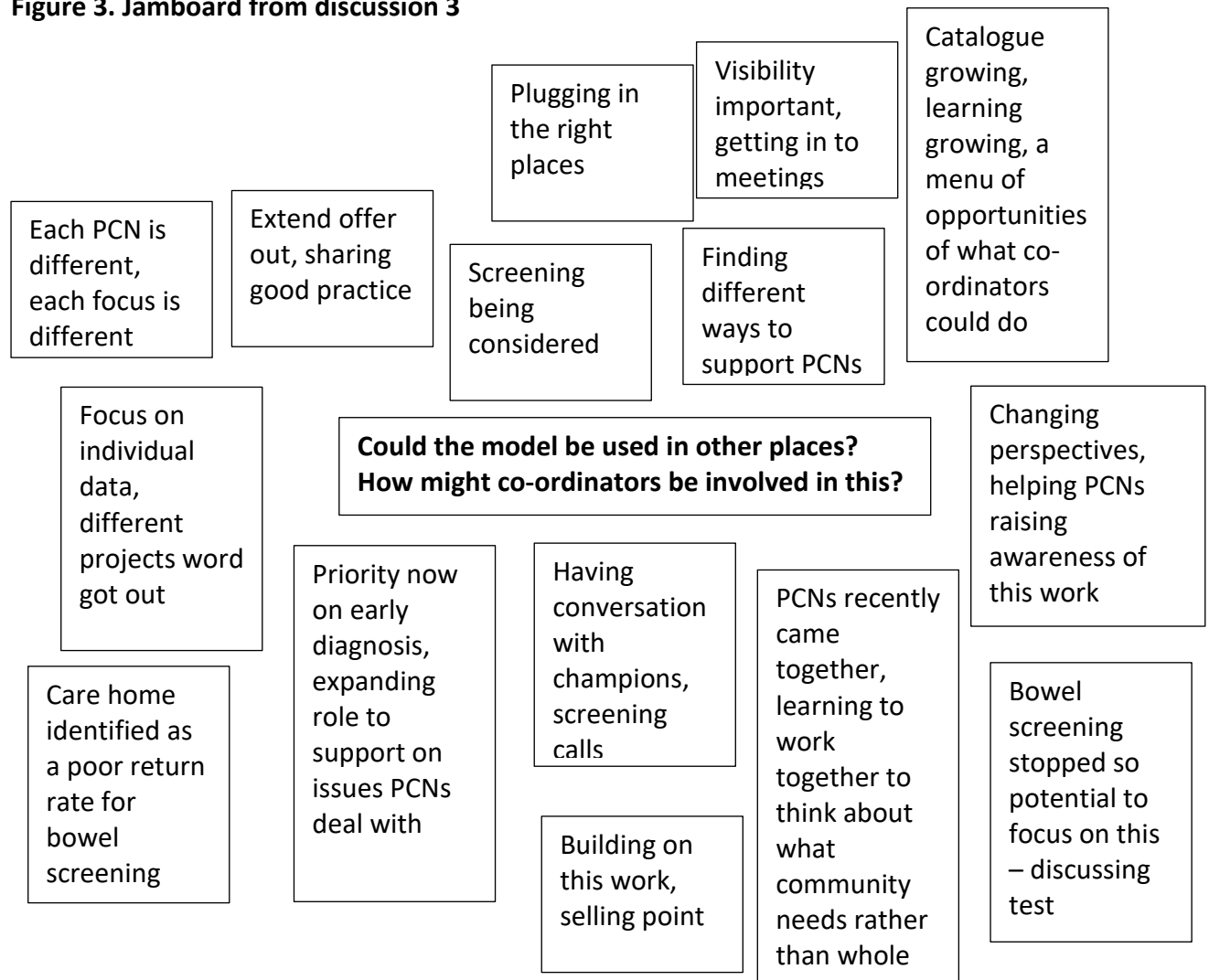
genuinely interested in their practice and their population” and providing services that met their needs, but didn’t have the capacity to do any scrutiny of data themselves.

Participants reflected on the crucial importance of CS&ACs being embedded in primary care. Their positioning was key because they were not seen as standalone people who came in and looked at the data, but were part of the team. The skills of the CS&ACs was also recognised, with their role described by one participant as “a blank canvas” and in order to begin examining and using data they had to navigate and develop complex systems.

Another lever which drove the initiative was a city wide audit, to see who might struggle and who might not when screening was re-started post covid-19 pandemic temporary stoppage. This was described as forming part of a system context for change, with improved knowledge and understanding of what else was happening in the system and what needed to be done to drive improvement, with finance to support this and collaborative working with the PCN to make the initiative happen. The timing of the proposal was described as “quite fortuitous” as some underspend per PCN had been identified and there were discussions regarding what should be done with it; Saturday clinics were proposed as so the funding was there for this.

There was discussion regarding the potential for this model to be rolled out further, and what the role of the CS&ACs might be in that. Participants viewed extending something similar to bowel screening as being unlikely as the programme is nationally driven, and getting a sample in a clinic situation might be challenging.

Figure 3. Jamboard from discussion 3



Perceptions of effectiveness

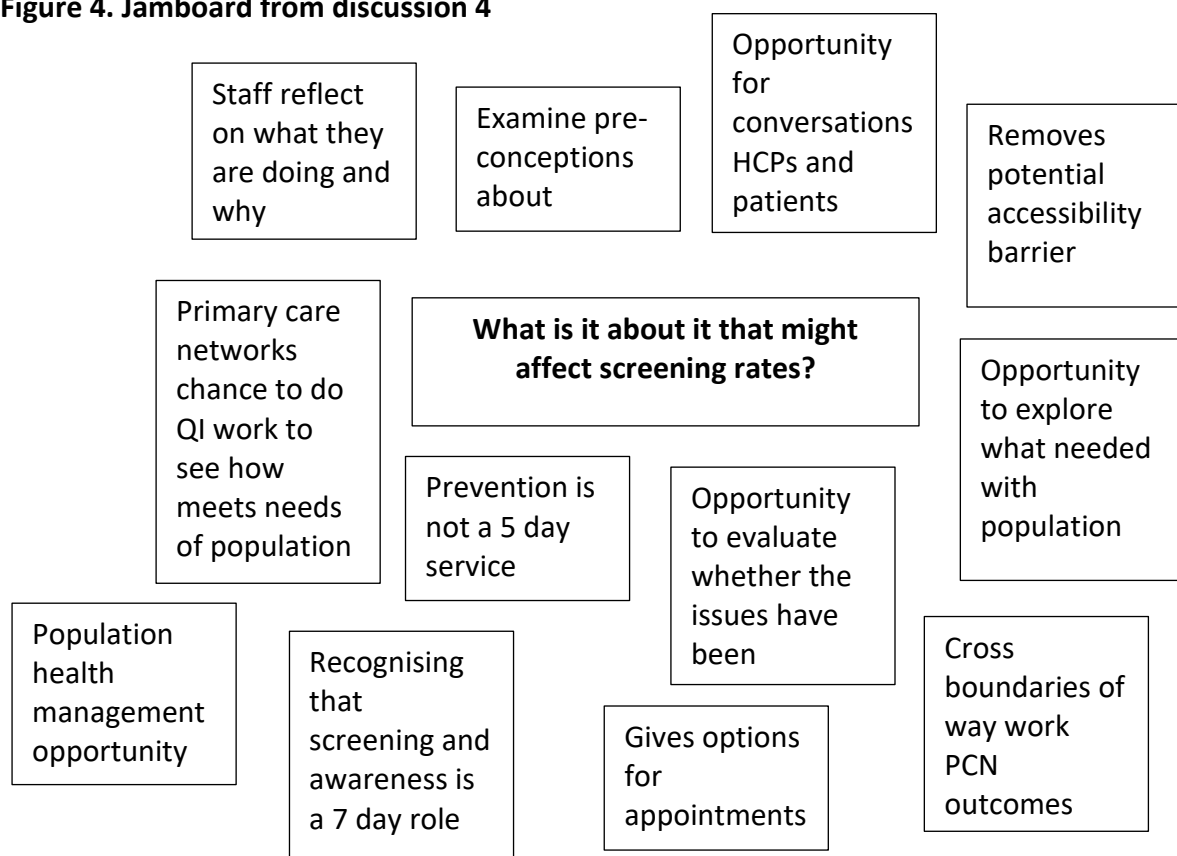
The initiative was described as being in its early days, with up to date screening rate data not available at the time of this workshop. It was also mentioned that comparing screening rates before and after evaluation of the initiative was challenging as the Covid-19 pandemic impact had been sizeable, and for a while screening had stopped. The landscape for population health interventions has changed substantially since the pandemic, for example influenza vaccination has increased. The data on participation could also be skewed because people are more reluctant to come into surgeries due to the fear of infection. Losing the footfall through practices will also have the effect of reducing opportunities for publicising the initiative via posters.

The introduction of the hub was described as giving opportunities to do some awareness raising and utilise the local press. This had enabled getting out some of the messages regarding the importance of cervical screening, and the work of the hub, and to talk about this across Leeds.

A directly observable impact was the sharing of learning with other PCNs, with reports that three other PCNs were taking on nurses to provide cervical screening clinics for those who are not attending. This was driven by the data compiled for their areas and participants perceived that “this wouldn’t have happened if the CS&ACs hadn’t done the work”. The work of the CS&ACs was described as influencing “how people are using their nurses”, with evidence of more specific targeting of groups of patients as indicating that the work of the CS&ACs is impacting elsewhere.

It was suggested that there is a greater opportunity for the CS&ACs to create a role in the PCN rather than individual GP practices. It was perceived that PCNs are starting to see the value of someone focussed on and co-ordinating efforts around screening uptake [please note, uptake used colloquially]. While it might be difficult for an individual practice to fund someone, working via a network meant more of an opportunity to look at funding initiatives.

Figure 4. Jamboard from discussion 4

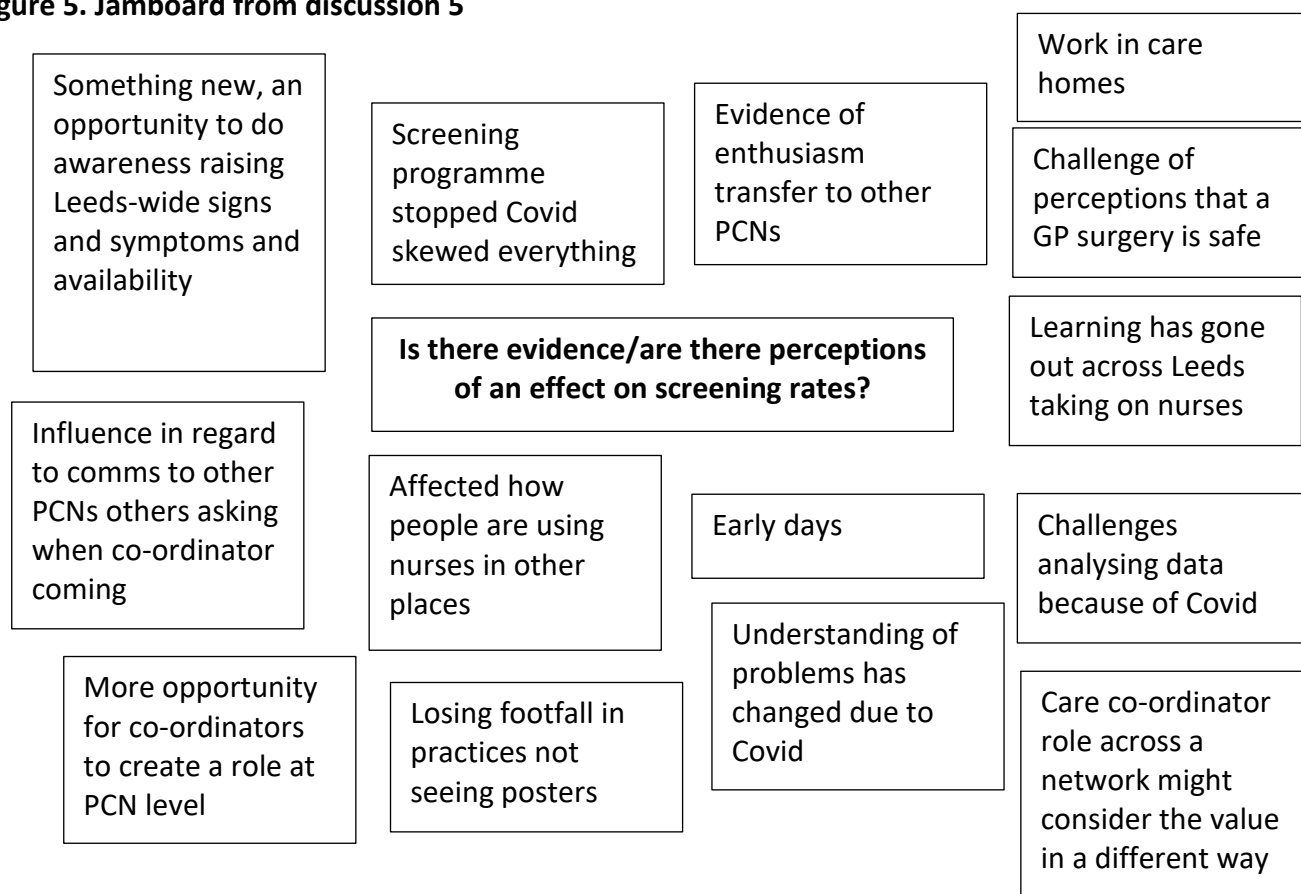


Discussions regarding the effect of the work of the CS&ACs (such as those outlined above) often related to what might be termed soft effects – described by one person as “a quiet impact”. These effects were attributed to “other people looking on with interest”. For example, the work of the CS&ACs was encouraging PCNs and practices to start looking at different ways to engage with patients. A cervical screening video was mentioned as being developed and shared across practices in Leeds, which participants attributed as being partly due to the soft effects of the CS&ACs’ work. The “looking on with interest” had led to neighbouring PCNs saying “when is my Yorkshire Cancer Research coordinator coming to me?”, with participants describing evidence of enthusiasm, and transferring findings to other PCNs, such as additional screening and considering how things might be done differently or be more nuanced to individual communities. An example given of this was the work by one CS&AC looking at screening uptake [please note ‘uptake’ is used colloquially] amongst care homes and how residents might be better targeted for screening, with other PCNs reportedly now also looking at this.

The effect on PCNs across the city was reported to be influenced by how long a PCN had been operational, as some were very new to working together and were still establishing how the PCN would function. The experience of the CS&ACs was that their influence depended on which other staff were within each PCN. It was important that CS&ACs were a visible presence within them. One participant saw the potential for CS&ACs to be a part of Extended Access working on population health management “linking in to everything we do”.

One of the CS&ACs emphasised that each PCN in the city is totally different, their focus needs to vary as they have different populations. The work of the CS&ACs showing what local data analysis has been done, age group and street level and differences across the city has led to more and more PCNs seeing the value that the CS&ACs are providing. The role and activities of the CS&ACs was described as an evolving “catalogue” which was developing a menu of opportunities showing what has been done, and where there are potential opportunities for further extension of the role. The CS&ACs acted as a means of sharing good practice between PCNs, and as their activities became more clearly defined, they are able to provide “a menu of what we can do”.

Figure 5. Jamboard from discussion 5



Workshop 7 - January 2021

This workshop explored the work and changing role of the CS&ACs, with eight of them present for the session including some who had been in post since early in the programme and others who were recent recruits. This provided an opportunity to explore the mechanisms of introduction to the role, and how and where there were similarities in their work. See Figures 6 and 7 for jamboards used during the workshop to note discussion points.

Experience of the CS&AC role

Recently appointed staff described how the existing CS&ACs were providing induction and support via regular, informal catch ups and other more formal meetings. It was noted that induction for new staff by existing CS&ACs had been time-consuming as staff were joining the programme at different dates, so everything had to be repeated on an individual basis. This had put additional pressure on existing CS&ACs. As the size of the team was now growing larger (recruitment had been substantially delayed due to the Covid-19 pandemic), induction and

mentoring was now shared amongst more staff. Some staff perceived that the induction process could have been more formalised, with specific meetings to provide clear direction regarding the role. One person recalled how they thought they would be introduced to key people from day one but this did not happen, and they had been surprised how long it took “just to get to square one” in the role. Learning from each other had been a vital part of establishing oneself in post, but each PCN was different creating different needs and challenges.

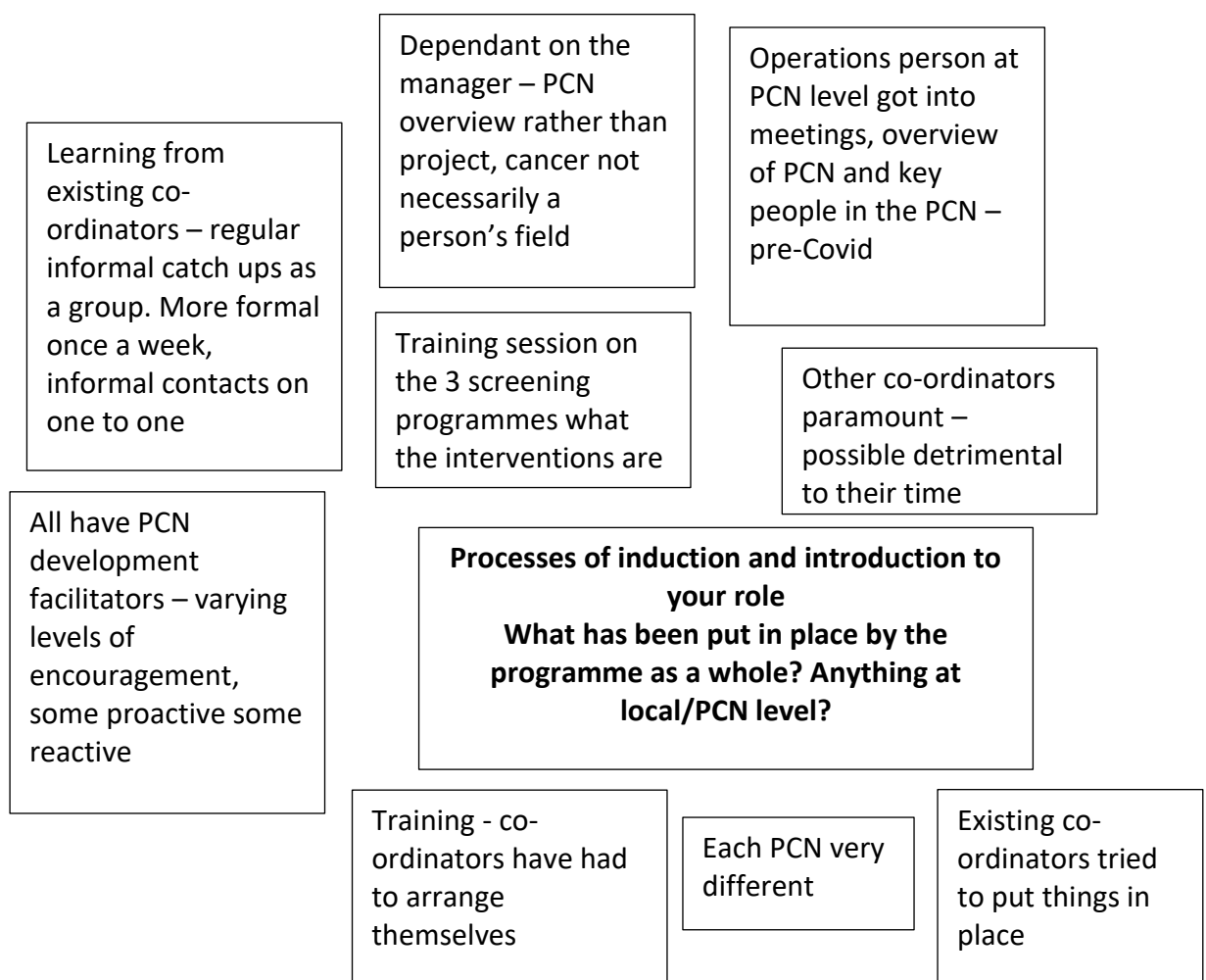
A training session for new CS&ACs had been provided, covering screening programmes, barriers etc. Some participants reported that they had felt pressure to achieve outcomes in a short time frame, but now the programme is being extended for a further six months this had been alleviated. Some CS&ACs described how a lot of training had to be organised by themselves, and emphasised that it would be helpful to have a package of training in place. Training was perceived as being “very late coming” with some participants describing how they had been in post a while before receiving any training. Participants identified a set of core areas they need to be trained on – particularly SystmOne and data analysis as these are core things that would be useful. One person described how they had assumed the CS&ACs would have a data pack for each of their areas, and this would be useful for new starters to have straight away.

Those present emphasised how their experience of each PCN had been very different. For some, key people had things set out such as expectations and role at the outset, they had been given an overview of the PCN, and had got into meetings quickly. Others reported less clarity in role, challenges starting to collect data, and competing demands. Help and support within the PCN had seemed to depend on who their line manager was and where their interests lay. For some participants their appointed line manager had only a limited understanding of the project. It was emphasised that while a line manager could fulfil the functions in terms of HR, not having a full understanding the project created difficulties. A further area of differing experiences of being a CS&AC was related to varying levels of interaction and enthusiasm for the CS&ACs role amongst primary care development facilitators. There were reports that sometimes the significance of their role was not fully appreciated. Working remotely during the Covid-19 pandemic had made establishing

themselves in their role more challenging. One person described how they were uncertain which meetings to attend or not attend, as while many may be interesting, some are not relevant to their role.

CS&ACs described their role as “ever changing” with a need/opportunity to “create their own work”. While this provided flexibility, it could equally be detrimental as they didn’t know who to go for certain things. Participants described real challenges getting on to SystmOne and EMIS, and other IT issues.

Figure 6. Jamboard from discussion workshop 7

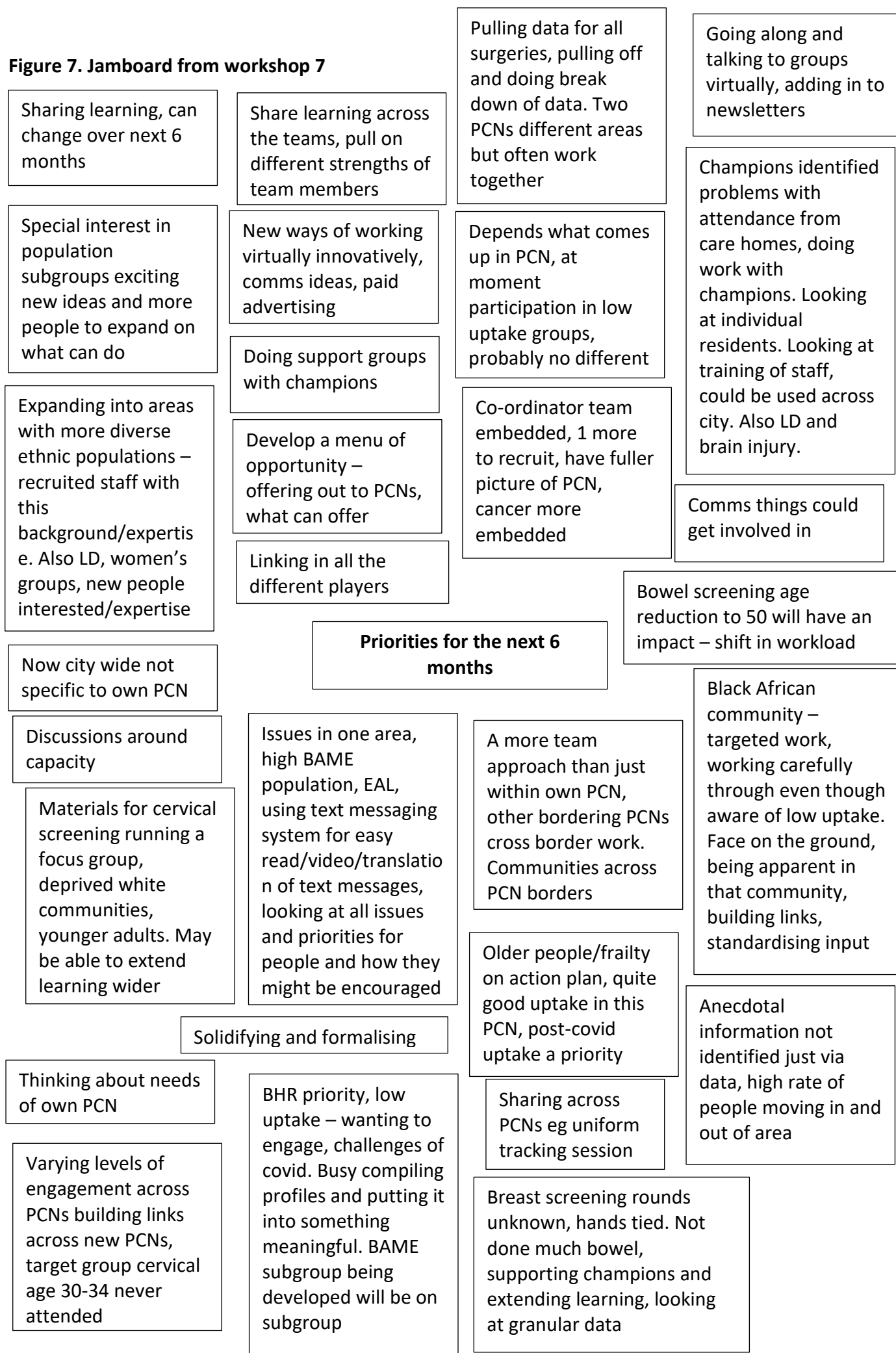


Focus of activities

When asked what their area of focus would be for the forthcoming six months, CS&ACs varied considerably in their response. This variation supports the comments above that the role for individuals was ever changing, flexible to needs and wants, and dependent on the PCN.

- The intended focus for one was linked to the forthcoming reduction of the bowel screening age, which would have implications for non-responders and low participation groups.
- For another the focus was expanding learning into more diverse ethnic populations and learning disabilities, and joining up across PCNs.
- Targeted work with Black African and South Asian populations building up relationships at ground level was suggested by one CS&AC, and
- Another was planning to examine the area of older people and frailty in regard to accessing screening.
- Older white British people in poverty was mentioned as a potential focus by another.
- Another target group mentioned was those with a cervix in their 30s who had never taken up cervical screening.
- Looking at the written information provided to minority ethnic groups was suggested by one person.
- One person described trying to extend reaching and targeting groups using virtual means, and building on the individual skills and interests of the newly extended CS&AC team to continue to build their role and activities.
- Others described aims of building networks and activities, looking at how work can be transferred across PCNs and across the city rather than just being PCN specific. For some staff the target was further getting to grips with the data.

Figure 7. Jamboard from workshop 7



Public perceptions and screening behaviours

Workshop 8 - April 2021

In workshop 8, we explored with colleagues from the Leeds Cancer Awareness Project, what the key barriers were for members of the public to respond to screening invitations. The discussion was based on both their extensive experience gained from their work, together with findings from a recent workshop, which they had carried out exploring the issues with members of the public. The obstacles to screening described fell within the main themes of knowledge and understanding; emotions; accessibility; and religious and cultural.

Knowledge and understanding

A challenge reported was that people invited for screening sometimes had little understanding about what would occur when they attended an appointment. This seemed to be a particular issue relating to cervical screening where the letter received tends to provide information about why she should attend, but little or no details of exactly what would happen. There was a suggestion people had to be proactive in searching for information, and there could be little awareness of screening until a letter was received.

There was discussion regarding potential differences between practices and areas as some GPs send out additional information in addition to the standardised centrally produced letter, whereas others do not. It was perceived that additional information may be beneficial to alleviate some people's concerns, and worries could be taken away before they attended. There was the suggestion that a role for CS&ACs could be to address differences between practices and encourage all GPs in their area to have a standardised pack. This would ensure a "level playing field". Another suggestion was that adding a QR code to the appointment letter would be a good idea, which gave links to NHS sites providing more information (which could be in the form for example of videos). Challenges in providing information to people who do not speak or read English were highlighted however. It was emphasised that translating written information into other languages does not resolve the issue for those who are unable to read their primary language. Greater use of diagrams and pictures may help to address literacy obstacles.

It was suggested that the word “invite” is rather soft and potentially the wording in correspondence could be more forthright. Perhaps phrasing it as “your appointment is this time and call us if this is inconvenient and we can rearrange” which is similar to hospital appointments and therefore potentially familiar, might be a beneficial alteration. However, a barrier which was noted is availability of appointments, with reports of people ringing and being unable to get through. This was particularly in regard to those that are eligible for screening attempting to book appointments for cervical screening, where, like breast screening it is necessary to make an appointment.

The bowel screening process was noted to be very different from cervical given that it arrives in the post. There were reports from some patients that they didn’t like the bowel kit arriving on their birthday, and despite the leaflet contained in the package, some people were uncertain how to do the test. A particular obstacle for bowel screening is a perception that “it is messy” and people “don’t like to mess around with their poo”. It was pointed out that all the information is sent out in English for bowel screening, with around 200 other languages spoken in England.

The existence of misinformation in communities was outlined, for example a belief that having a mammogram causes cancer had been voiced by some individuals. These people had told the story of knowing somebody who went for screening and had a diagnosis, and three weeks later they had died. Some communities simply don’t talk about cancer and cancer screening. There is a need for communications to be via people who are already working with that community, for example people on the ground community leaders etc. It was suggested that for breast and cervical screening it was important to ensure partners had a full understanding and were involved.

Emotions

Discussion regarding emotions focussed around the tendency for people to avoid anxiety and discomfort. While advertising and publicity regarding cancer emphasises that early detection saves lives, some people instead adopt a position that they do not want to be diagnosed. This

may be associated with the fear attached to it, and a persisting perception that cancer is always a death sentence. There was a common (and understandable) fear of the unknown, the point was made that “who wants to be told they have cancer” and instead some have “their head in the sand and would rather not know”.

It was suggested that at a PCN level staff could be trained to be more tolerant of people who struggle with emotions regarding screening. There is perhaps a need for first appointments for screening to be longer than subsequent ones in order to allow time for people to fully discuss any issues. In particular regard to cervical screening, some people may have had childhood trauma which makes them not want to be screened, and while the leaflets say that it is painless this is not always the case for everyone.

Accessibility

The place and process of bowel, cervical and breast screening differs, with breast and cervical requiring travel to a clinic/hospital. The challenge relating to childcare for many of those with a cervix attending for these screening appointments was highlighted, particularly where there was no partner or family who could take care of children to enable them to attend. Some have no option but to take children with them to a surgery. While public transport was described as “quite good” in Leeds there are gaps in routes, with some surgeries being more easily accessed via public transport than others. Barriers for people who struggle to attend during normal worker hours were mentioned such as night workers or those who cannot take time off.

The potential to use brief advice conversations to advocate screening was mentioned, with a GP potentially ideally placed to do this. But it was recognised that in a busy consultation it was likely that they may not have time. It was perceived that CS&ACs may have most options to take action on cervical screening as they are carried out in the practices, whereas bowel and breast came from the national hubs.

Religious/cultural

While the value of using community leaders to support and inform was emphasised, the challenge of identifying exactly what and who was a community was also mentioned. This was easier for some population sub-groups than others. Trying to find a group and spread the message was helpful in the hope that the group would pass the information on. Particular issues contacting people who are from the travelling community was mentioned. Particular issues relating to modesty in certain communities was emphasised for the intimate breast and cervical screening procedures.

Other barriers

Challenges for people who have a learning disability was highlighted, as they are often relying on a carer to take them to a screening appointment. Self-examination of breasts is also not easy to do if you have disabilities. It was described how pulling away is seen as withdrawing consent, but this may just be anxiety requiring further information and reassurance.

Workshop 9 - May 2021

This workshop comprised a session for members of the public aiming to explore perceptions of screening including consideration of how a role such as a CS&AC at General Practice level may promote participation. The workshop was planned with input from our public advisory group, which assisted with preparation of an advertising flyer and avenues to promote the event. We advertised via colleagues in relevant organisations, online groups, local newsletters and other media in Leeds, but participation was low, with five people present. These people all lived in the Leeds area, were mostly retired (four individuals) and were interested in local cancer services. One had direct experience of cancer care, one had links with voluntary services, and the others had family/friends who had used cancer services, all were eligible for at least one of the screening programmes

Awareness of initiatives to increase screening uptake in Leeds

While the CS&AC programme does not have a focus on working with patients and the public in the area, we thought it would be interesting to know if there had been any local media coverage about the initiative, or whether anybody had awareness of any other initiatives in Leeds which aimed to increase cancer screening rates. Some of those present were aware of a Women's Centre (Shantona Women's and Family Centre) which they believed distributed information about and promoted screening for breast and cervical cancer. Participants spoke about the role of hospices as offering support for those diagnosed, but apart from the Women's Centre could not recall anything specific in Leeds that was aiming to encourage people to go for cancer screening. We asked the group about potential barriers to taking part in screening in Leeds. Their responses are summarised in Box 1 below.

Most of the factors identified echo the data from workshop 8 relating to knowledge and understanding, emotions, accessibility and cultural/religious influencing factors. There are additional details regarding cultural barriers, together with highlighting the impact of the Covid-19 pandemic.

Box 1. Potential barriers to taking part in bowel, breast or cervical screening

Embarrassment.
Too busy.
Cultural – difficult accepting having cancer do not want to share diagnosis with others.
Poor English, relying on child to translate, struggling to read in other languages, no female in family to come to translate.
In some cultures cancer is a taboo, prefer to deal with on own.
Need to have access to trusted faith leaders.
Those having a history of abuse, would prefer somebody with them but can be difficult to arrange this.
Receptionists not always supportive.
Not a priority, other things to do.
Difficult to get there (work, child care, transport, accessibility eg steps).
Community leaders change messages from that intended to be disseminated.
Lack of knowledge about screening and/or cancer – not able to read, some groups not aware.
Don't want to find out, fear that it would result in a change of lifestyle and having a lack of control.
Some people need support to get rid of fears, currently no easily available contact for support.
Covid impact – need to build trust back up, delays in appointments.
Due to Covid trust lost in NHS to be safe, third sector trusted more.
Waiting lists are discouraging.

Suggestions for ways to increase uptake comprised firstly, giving people knowledge and understanding of cancer and screening when people are younger; there was a perception that adults are frightened of telling children about cancer. The communication should include information which focuses on people learning to check themselves. It was suggested that avenues which could be used more to promote screening were parent groups and mother and baby groups, local radio, job centres, and religious groups. Participants suggested that there should be an emphasis on having support around screening, as currently it was perceived that all the support was around diagnosis and treatment. A key part of screening was around building trust with people.

Information about screening

Participants emphasised that successful communication usually takes place in more than one way, so there were considerable limitations in just sending one letter. They suggested the key factor of having somebody to talk to, as “talking to gets more people in, not just letters”. The group perceived that there is a need to think differently to reach those who don’t currently take part, and not rely on people taking up screening just because a letter comes through the post. It was perceived that “the younger generation don’t look at letters”.

Participants described how most information about breast screening that accompanied an appointment letter was about how to get there and parking etc. They couldn’t recall any information which gave detail on exactly what is going to happen at the appointment. In their experience there was no number that would get reliably answered for queries regarding breast screening, with an appointments line which “nobody picked up”.

Role of primary care and communities

Participants recognised the importance of GPs and considered that they could have more of a role in advocating for screening. It was perceived that at a practice level there should be more contacting of people, and more encouragement of early screening. Routine check-up appointments could be used as an opportunity to ask about screening. Some participants described how people could be confused over what GPs can and cannot do with regard to screening, and this uncertainty could leave vulnerable people outside the process. The point was made also that a lot of people are not registered with GPs so this may exclude them from screening systems.

There were comments that there could be better working together with patient engagement groups at the GP surgeries, for example working with GPs who are leading initiatives to increase screening. Following the Covid-19 pandemic there was a need to be working differently now, to pay a greater attention to see what circumstances people are in. The importance of ensuring that the voluntary sector is involved in any initiatives was emphasised, and also making sure that the community know what is happening. Participants considered there was potential for greater use of social media, and potentially WhatsApp at a local

practice level. There was a suggestion that TV Asian channels and local radio could be used more. A final suggestion was that people who have been through cancer, and who have life experiences could be used more as advocates and champions for screening, especially those who of the younger generation. Some participants discussed the potential for greater links with schools to be established.

Evolving strategic direction of the programme

Workshop 10 - June 2021

This workshop was carried out with senior staff within the programme to discuss how the strategic direction had evolved over time. Four people were present. As a basis for the discussion, we presented the initial logic model which had been developed from workshop 1 carried out 15 months earlier. This structured the discussion around the elements of the programme, levers of change, influencing factors and outcomes and impacts. Additional elements were added to the model in red, with the black items the original model (see Figure 8).

Elements of the programme

We were interested to review and reflect on the expected role of the CS&ACs and activities versus how the programme was operating currently. Participants reported that there was less emphasis on developing community partnerships than had been envisaged, and the programme instead was very much focused in primary care.

The development of targeted action plans for each locality, drawing on data to understand local variation and what is working or not working, was identified as the core work of the CS&ACs at that time. Data mining was added to providing data analysis packs.

One area of discussion was the role of the CS&ACs in identifying and delivering education and training. The original model had included reference to both identifying training needs and delivering training. Participants in this workshop reported that delivering training was not in

the CS&ACs' role, they were instead doing helpful work having conversations about training needs and "if a gap is identified having a facilitative role to bring training in".

The role of the CS&ACs as taking a topic lead and promoter of screening was added to the programme elements, facilitating staff development and being used as a resource. The topic leader role was reported to have not been originally envisaged, but participants reported that CS&ACs are being perceived as the top-level experts in cancer screening by colleagues. CS&ACs were described as fitting into the work the CCG are doing, and also "plugging in to wider partnerships" both at a strategic level and within smaller task groups. Participants perceived that they were starting to be and have been a visible presence within PCNs, and being increasingly well recognised for what they do locally.

In a previous workshop we have described the "soft effect" of the CS&ACs, and the elements of the programme described in this workshop including promoting the informal transfer/sharing of knowledge, sharing good practice and providing a facilitating and supportive network all seem to relate to operating at the level of more informal routes of influence and potentially effects.

Participants described how the particular skills and expertise of members of the CS&AC group had influenced the direction and activities within the programme. As the team has evolved and grown the programme leads have identified gaps in staff skills and backgrounds and further recruitment has been an opportunity to complement the strengths of existing team members. There have been opportunities to use/draw on the particular expertise of individual staff. While Covid-19 had led to the expected recruitment being considerably delayed, having fewer CS&ACs than PCNs had been beneficial in enabling CS&ACs to operate on a wider footprint. Rather than each CS&AC being PCN-specific, a model was increasingly being adopted whereby CS&ACs take a lead on a topic across PCNs depending on what has been identified and who is best placed to offer expertise. An example given was of a CS&AC with a data background, which has really helped across the programme, as there has been data they have been trying to collect but not had access or capacity to do this. One participant commented that co-operation between practices and working across an area provided

efficiencies, and was also a reflection of the general progression of what is happening in primary care networks.

The rolling recruitment process as a result of the pandemic was described as having both benefits and negatives. It enabled the programme to “learn as we go, see what skills are required, and revise job descriptions”. But the downside has been a challenge for establishing team dynamics, and it had been found that it was difficult for some to join a team that is expanding and growing. Considerable challenges with recruitment and retention of staff had been experienced which it was suggested may be because the job did not qualify for an NHS pension, which would be a considerable deterrent to anybody considering a secondment or re-employment from an NHS post. Having a role which was changing and evolving particularly at first was potentially an issue for applicants and those in post, and the duration of the post may also have had an impact on recruitment.

In regard to the item on the initial logic model “facilitating communication at a strategic level”, participants at this workshop considered that instead CS&ACs have taken a hands on approach to communications at an operational level as the programme has its own communications system.

In regard to the item “co-ordinating provision of care by the right people” the participants concluded that this hasn’t become part of the main role, although linking other services together was within remit. Signposting was left in as an element of the programme as it was reported to happen as links were made with community services post diagnosis, post treatment and beyond.

Levers of change

The key area that participants thought would make a difference was their work on data analysis and drilling down to scrutinise screening uptake in small, specific populations. Examples given included being able to identify patients who had hysterectomy surgery, and work identifying and targeting people with learning disabilities which was described as “a game changer”. Being able to scrutinise data at local level was key (for example drilling down

to a level of even just two streets) to look at where people weren't coming for screening. As described earlier, that was how the Saturday morning screening hub had developed. The PCNS coming together in a more co-ordinated way, plus having the capacity of the CS&ACs to do the data analysis has enabled change to happen.

Another key aspect of the programme highlighted was the way that work was tailored to each area and thus was context driven. Working opportunistically has also been an important lever of change. The example given here was that just being present at meetings has led to all sorts of conversations that hadn't been predicted, such as taking the opportunity of using the covid-19 vaccination programme to target patients, and utilising social media.

The model of CS&ACs working across practices was perceived as being an important and unique aspect of the programme. Whereas the Cancer Champions staff are focused around a single practice, CS&ACs work across Primary Networks (which is a main difference between the CS&AC and Cancer Champions). They are able to experiment with new things, and share their learning which was reported to have worked particularly well for certain groups.

Another lever of change was the context of the covid-19 pandemic. Participants described where previously activities were happening "in pockets", but then the pandemic forced practices to work together. The timing was therefore ideal for CS&ACs to have "parachuted" into this context. Participants reflected further on what difference the pandemic had made to the programme, and the consensus was that progress has been faster due to the need to get people together, ability to have instant access to key people, and an increased motivation to work collaboratively due to covid-19. It was highlighted that the pandemic had also "shone a light" on health inequalities, and cancer screening had been pushed up the agenda. One participant described the difference as "doors have been opened this year". The increased use of technology such as virtual meetings in primary care was described as "giving a lot of opportunities", and one participant described primary care as "jumping forward five years".

Influencing factors

We asked participants to reflect on factors which have influenced the implementation of the programme and potentially the effects achieved. The first factor identified at a previous workshop was “contextual variation”. Participants described this as “not being as significant as had been thought”.

Those present recognised that other services in the city had “put them in a good position to support them to get on track”. These other services had already been able to attract resource and investment. An example given was that intelligence gathered already by the Cancer Champions was utilised by the CS&ACs. Champions are not in post all over the city and participants noted that there are differences in practices that do and do not have champions.

While the covid-19 pandemic was an important lever of change, the effects were also described as having some adverse influence. Ad hoc conversations in the practices were described as being important, and these had not been as easy during covid when staff were working remotely. While it was acknowledged that remote working had made it easier to work with less commuting and easier access to people for virtual meetings, “the down side that you can’t meet and have that personal, relationship building” was perceived to have had an adverse effect on team dynamics.

Delays caused by the pandemic also affected recruitment of CS&ACs, and the programme had been considerably under capacity for staffing. Participants reported that in general the programme had “adapted well but have had to move people around to cover, which wasn’t the original plan.” CS&ACs in post were having to cover a larger area, which meant the programme was heavily leaning on the existing skills, areas of interest and expertise of staff. This led to some changes in the way the programme was originally envisaged, and instead of CS&ACs working in specific PCNs, there had been “across city working” and “flexible working with sites”. CS&ACs had been given a focus to work on that they had existing expertise in. The original model was locality based but had evolved as a necessity due to the reduced team, but it was perceived that rather than being detrimental it had “actually fitted in to how PCNs were working anyway”.

Participants reflected on the crucial importance of awareness and support for the programme at a senior level. They described how there had been “some miscommunication about what data was required” for CS&ACs to analyse which had created some initial challenges. It had been key to “place the weight at senior level that full access to the data is crucial”.

Outcomes and impacts

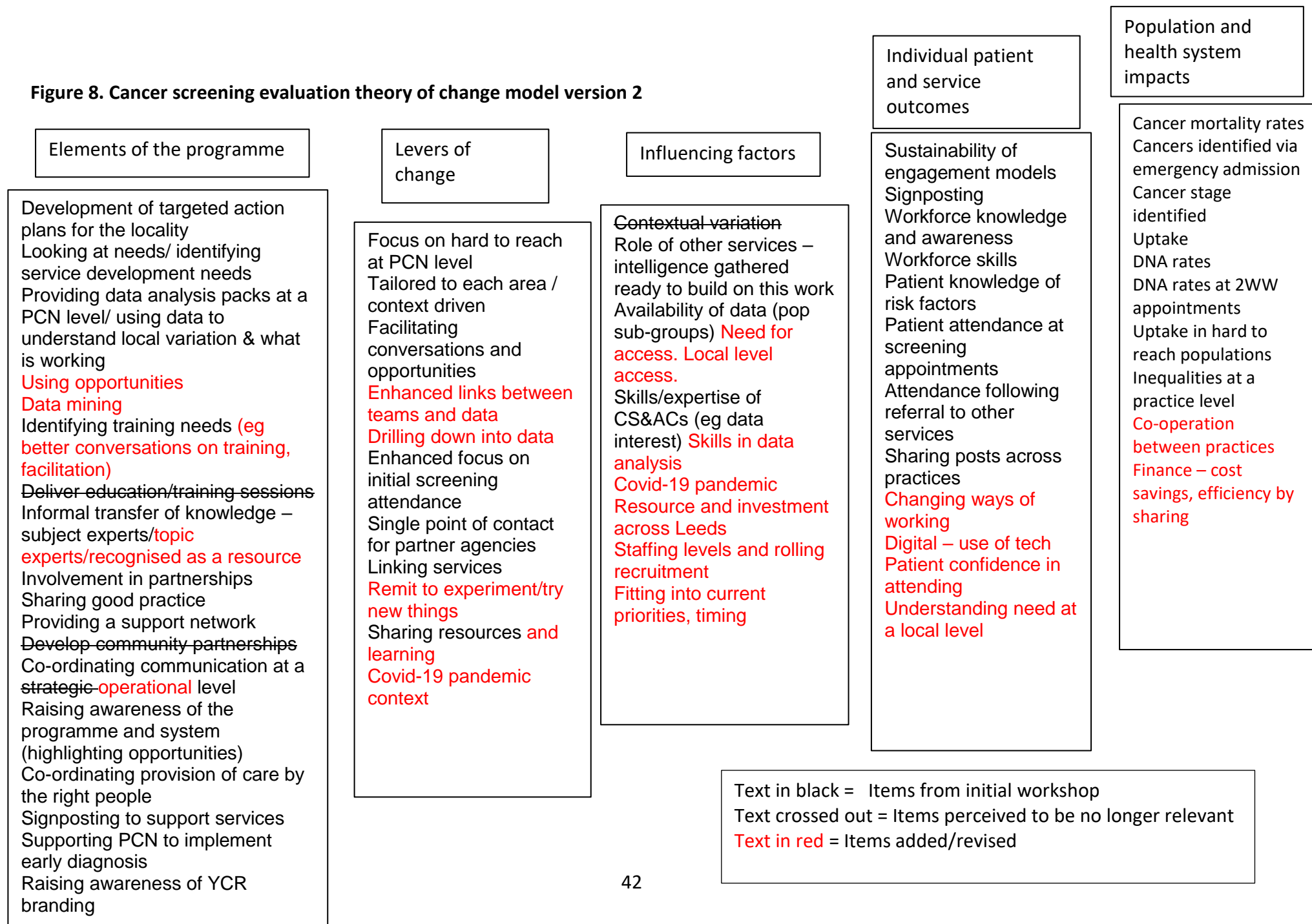
During the workshop we explored whether and how the expected outcomes from the programme had evolved, particularly given the influence of the covid-19 pandemic. We revisited the logic model which had been developed from the initial evaluation workshop to explore how and where there had been changes or continued focus (Figure 9).

Participants reported that the key performance indicators were being reviewed, but it wasn't expected that there would be changes. They discussed how increasing patients' confidence to come for screening was a new challenge which hadn't been foreseen pre-pandemic. This outcome was added to the logic model together with: changing ways of working; increased use of technology; and greater understanding of need at a local level.

At a wider system level, co-operation between practices was added as a potential impact of the programme, and also economic outcomes were added as participants perceived that there could be cost savings including as a result of better working together/sharing.

Discussion regarding precise pathways between elements of the programme and effects, focused on how working with younger age groups will have an effect on non-attendance rates, and how targeted communications may have an impact on screening amongst populations who are harder to reach. It was also suggested that improved data scrutiny will lead to greater action on inequalities and groups that are performing the worst on screening rates.

Figure 8. Cancer screening evaluation theory of change model version 2



Further analysis of the elements of the programme

Workshop 11 - November 2021

In this workshop we aimed to further explore the activities which the CS&ACs have been engaged in, are currently engaged in, and expect to be engaged in during the final phase of the programme. As part of this we wanted to ascertain whether it was possible to provide an indication of the proportions of time allocated to each of the three cancers, in order to inform our evaluation of impact. Five members of the CS&AC team were able to attend. This is very challenging element of the evaluation that we will continue to explore.

Initial discussion focused on endeavouring to estimate **proportions of time** allocated to breast, bowel and cervical screening. The evaluation team recognise how challenging this activity is, and that the estimates given represent participant perceptions and “best guesses” rather than being based on data. Participants also highlighted how there are differences between PCNs and practices, and different weeks and months. Nevertheless, despite these cautions, those present were able to reach a consensus view that a reasonable estimate of time allocation since the programme had started was 5% for breast screening, 25% for activities relating to bowel screening, and 70% for activities relating to cervical screening. It was perceived that this split has roughly been the same since the programme started. The expectation was that in the following six months, activities relating to breast screening would be a higher percentage than currently, there would “still be a bigger focus on cervical but it would tip slightly”. The consensus estimate was for breast to increase to 15%, bowel to reduce slightly to 20%, and cervical to reduce slightly to 65%.

The difference in regard to future breast screening proportion of time was reported to be due to a past lack of information on breast screening rounds, so it was not possible to work with PCNs before/around the time that those eligible for breast screening in that area were due to be called. This information had only become available in the past month or so.

While the amount of effort allocated to breast screening was expected to increase, participants highlighted that this would depend on the timing of the screening rounds as residents in some areas of the city would be contacted for screening in Spring or Summer

2022, but others not until the end of 2022, and others may be in areas which have already been contacted. Participants distinguished the work that had been possible in regard to breast screening from their activities with bowel and cervical, “breast has been information, bowel and cervical can be more proactive, chasing non-responders, but breast is national campaigns, education and awareness....so a slightly different stance”.

Activities to increase the uptake of breast screening mentioned included being involved in Breast Screening Awareness Week **events**, attending six-weekly **meetings**, using **opportunistic situations** such as Covid-19 vaccination centres to distribute materials, and providing **information to practices** on how patients can re-book if they miss appointments. Input was described as often being ordering and providing **resources**, such as posters and leaflets in different languages. Plans for future activities encompassed – establishing a **process** for contacting non-responders and **exploring roles** for following up on non-responders within practices, working with a Communications Officer to look at communications ahead of patients receiving the screening invitation, producing a **template** for practices, providing information to go to community groups, and information for practices. Also, developing information or perhaps a text message system for patients including people with learning disabilities providing practical tips such as what to wear, what position to put your arm in when you have screening, and what to do if you have missed the appointment, and potentially making a video.

The slide used during discussion to summarise activities, and further added to by CS&ACs following the session is provided below (Figure 9).

Figure 9. Summary of activity relating to breast screening

Activity current/planned	When started or to start
Develop text message template for comms practices	November 2021 12 week effect March 2022, legacy effect
Processes for contacting non-responders – who responsible, developing safety net, how to re-book, role of screening champions/care co-ordinators	November 2021
Developing information for PWLD and culturally diverse groups	November 2021
Developing video with breast screening service	November 2021
Opportunistic links with eg vaccination service – provide with resources including in other languages	November 2021
Press release to local media sent to practices to coincide with breast screening awareness month (article in 3 local newspapers). Resources sent to practices.	October 2021
Data analysis of breast screening coverage before/after Covid-19 lockdown for PCNs to understand different and to plan work on how to bring figure back to pre-covid levels	October/November 2021
Breast screening awareness through community organisations ie breast feeding groups, newsletters, social media	January 2022

Activities aiming to increase bowel screening included producing easy read leaflets to supplement **information** coming from the hub, establishment of the Call for Kit **telephone call /face to face clinic** intervention carried out by screening champions, development of a bowel screening template, and production of information leaflets. Participants highlighted their work on identification of care home residents, which had been developed as a result of **data analysis** started 2020. This work had to be put on hold due to Covid-19, with reports of plans to pick this work up again and current discussion whether to base future work on information giving or training.

See Figure 10 for a summary of activities relating to bowel screening which was discussed during the session and further added to by CS&ACs following the workshop.

Figure 10. Summary of activities relating to bowel screening

Activities current/planned	When started/due to start
Call for a Kit clinics	2021
Providing advice on easy read leaflets/accessibility letters	2021
Identification of residents of care homes/information to staff	2021 started on hold to restart
Bowel screening template	Ongoing
Attending events	Ongoing
Bowel screening guidance document for screening champions and all practices across the city	Ongoing
Bowel screening telephone intervention targeting most deprived areas of PCN	November 2021
Easy read leaflets with learning disabilities	Ongoing
Work with community organisations in South Leeds for All (support people mostly 40 years+)	Ongoing
Bowel screening cards, posters and other comms	Ongoing
High rise tower block comms (i.e. 100's homes in most deprived areas)	New year

As outline above, participants identified that proportionally most time was devoted to actions intending to increase cervical screening.

Activities aiming to increase cervical screening included extended hours clinics, creating a video and a repository for resources online. Participants perceived that work with patient groups who might be considered “niche” was a unique element of their work, for example providing **information** specifically aimed at the LGBTQ+ community, and **guidance documents** for primary care staff. Other work on communications described included producing easy read **leaflets** for people with learning disabilities, and attending **events**. Plans for the future included consideration of training needs such as brief conversations for reception staff. An area of development planned had been pursuing follow-up phone calls for non-attenders, but this had proved challenging due to practice staff availability.

See Figure 11 for a summary of activities relating to cervical screening discussed during the workshop and added to subsequently by CS&ACs.

Figure 11. Summary of activities relating to cervical screening

Extended/out of hours screening clinics	January 2020, gap due to covid restarted June 2020, rolled out 12 to date, PCNs will continue
Pre-25 year old video	Exploring potential
Cervical screening video in 3 languages	October 2020 will be legacy resource
Transgender men/non-binary people, potential guidance document/information leaflets	Potential future work
First time patients – resources highlighting this age range	2021
Audit and easy read leaflet for people with learning disability provided to practices	2021
Examination of reception staff time available – potential for better conversation training	Upcoming
Web page resource for practices	2021, a legacy resource
Cervical referral cards, posters and other comms	Ongoing
Work with community organisations	Ongoing
Education, Health and Care Plan input	2022
Data analysis and coding	Ongoing
Screening template	
Care home audit for screening and eligible patients	July 2021
Cervical screening guidance document for screening champions and practices across the city	September/October 2021
Magazine article for Yorkshire Cancer Community to promote cervical screening and support with making an informed choice	May 2021
School/Children’s Centre staff and parent comms	Exploring potential
Work with University – postgraduate and mature students, Doctoral College	Early 2022
High rise tower block comms	Ongoing

Generic activities

Discussion during the workshop recognised that, while some activities were specific to particular types of cancer screening, work of the CS&ACs also encompassed actions which were generic to any form of cancer screening. For this part of the workshop we drew on the “Gap analysis” framework developed by the programme in September 2021, to consider generic activities relating to intended outcomes and objectives.

CS&ACs described Extended Access work as an example of **collaboration** at locality level, especially, where practices were working together as a hub to increase the availability of appointments for cervical screening. They described their activity providing support to the Cancer Champions via meetings across PCNs every 6-8 weeks where they give updates, share learning and resources with each other.

Participants identified that a key element of the role was **sharing knowledge** with colleagues, both via formal and informal avenues, bringing ideas together, and sending out information. Example given were using the Primary Care Bulletin to share information, reports from the project get sent out, and “a lot of informal stuff which we just pass on in meetings”. In regard to sharing expertise and learning – an example given here was co-production and delivery of training for the cancer champions. Participants perceived themselves as key **sources of information** for practices, “you do get random questions about cancer, I have become the cancer person”. Participants agreed that a key element of their role was researching and finding the latest information, and then feeding this back.

In regard to **individual patients** – participants perceived that “this is a very small part of the work”. Instead they emphasised that their role was to “facilitate the intervention to happen, we create it and then the staff in primary care would do it, we facilitate that, we are not the ones working on the frontline with patients”. Participants reported that “patients wouldn’t know who we were, we are not a trusted source”. In regard to improving conversations with people and patients - there were some reported instances of having conversations with community members and patients such as at vaccination centres and the Big Leeds Chat event, but these were few. Work specifically relating to culturally diverse communities was highlighted, with authoring of a report “Cancer Screening within Culturally Diverse Communities” which proposes strategies to increase uptake, including identifying a need for staff training in cultural competence.

Participants agreed with their role in **signposting**, but were hesitant regarding having any role in referrals to services, “referral is not something we would get involved in”. One person summed it up the role as “we can make recommendations, suggestions, use social media, website, always there to help but up to them if they want to do it. We are enabling and

facilitating them to do it”. Similarly, in regard to non-attendance rates – participants were clear that their role was **enabling it, not doing it**, “the two week wait etcetera is not us”.

Participants highlighted their work on **data analysis**, describing how they regularly analysed data from practices. They described their work contributing to the peer review process that practices and PCNs were engaged in, to support early diagnosis, identifying hard to engage patients and their contribution to **targeted action plans**. This was described as “taking up a lot of time” linking with the PCN team, the practice Champions, and Clinical Directors, and providing them with data, attending meetings and collating reports. Depending what the PCN wanted to focus on, the CS&ACs might have a further role in providing resources. But it was emphasised that “at the end of the day it is their action plan and what they want to focus on”. Another element of the data analysis activity is to carry out “**deep dive**” **explorations** of clinical systems. An example of this is the investigation of inconsistencies in recording ethnicity, which uncovered considerable challenges around accuracy and multiple coding for some patients. The CS&ACs also made available a folder of reports on the Clinical Systems to support practices to identify the diverse communities within their patient cohort.

CS&AC activities were described as often being “**trouble shooting** the challenges a lot of the time”. An important element was providing **local support** to PCNs and practices, although it was recognised that “some want support others do not”. This support was described by one participant as “being a third party to help them reflect on what they are doing, checking their processes and checking they are robust”. The supportive role required “intervening little and often”.

See the slides below (Figure 12) for the summary slides discussed during the workshop and added to by CS&ACs subsequently.

Figure 12. Summary of generic activities

Target outcome	Specifics of activities
Increased collaboration at a locality level across organisations	Through LCP work, working with practices, set up and organise meetings, give updates, share learning
Sustainable behaviour change at a workforce locality level including improved skills and knowledge and awareness of cancer.	In PCN, training, informal and formal, sending on information, use PCN bulletin, send reports project produced, passing on information
Sustainable behaviour change at a workforce locality level through consistent and improved conversations with people and patients leading to improved patient care	Opportunistic conversations at vaccination centres during lockdown, speaking to members of the community at The Big Leeds Chat Event, linking in with Leeds Cancer Awareness social media
Improved signposting (and increased referrals to services; e.g. One You)	Work with Link In Leeds. Referrals
Produce data analysis for practices/ locality level on screening uptake across national screening programmes	
Produce targeted action plans at a locality level based on population need	Chats with PCNs
Produce and deliver tailored communication materials to suit needs of the local population	People with learning disability, carers, staff
Support PCNs to provide expertise and share learning across Leeds, campaigns, docs, resources	Co-produced and delivered champions training package, sharing docs
Act as a point of contact for the community for both patients and also delivery partners – REMOVED	
Up-skill all practice staff to be more confident to discuss cancer screening. This approach was undertaken as it was more sustainable.	Training, sharing resources, articles etc.
Provider and deliver trusted sources of information for PCN workforce	Informal conversations,
Research and feedback re what is available	Providing resources
Supporting early diagnosis as part of peer review inc identifying hard to reach pts	Linking with PC development team and champions, attending meetings, providing data, collating reports, provide info and resources

Produce data analysis for practices/ locality level on screening uptake across national screening programmes

Produce targeted action plans at a locality level based on population need

Chats with PCNs

Produce and deliver tailored communication materials to suit needs of the local population

People with learning disability, carers, staff

Support PCNs to provide expertise and share learning across Leeds, campaigns, docs, resources

Co-produced and delivered champions training package, sharing docs

Act as a point of contact for the community for both patients and also delivery partners – REMOVED

Up-skill all practice staff to be more confident to discuss cancer screening. This approach was undertaken as it was more sustainable.

Training, sharing resources, articles etc.

Provider and deliver trusted sources of information for PCN workforce

Informal conversations,

Research and feedback re what is available

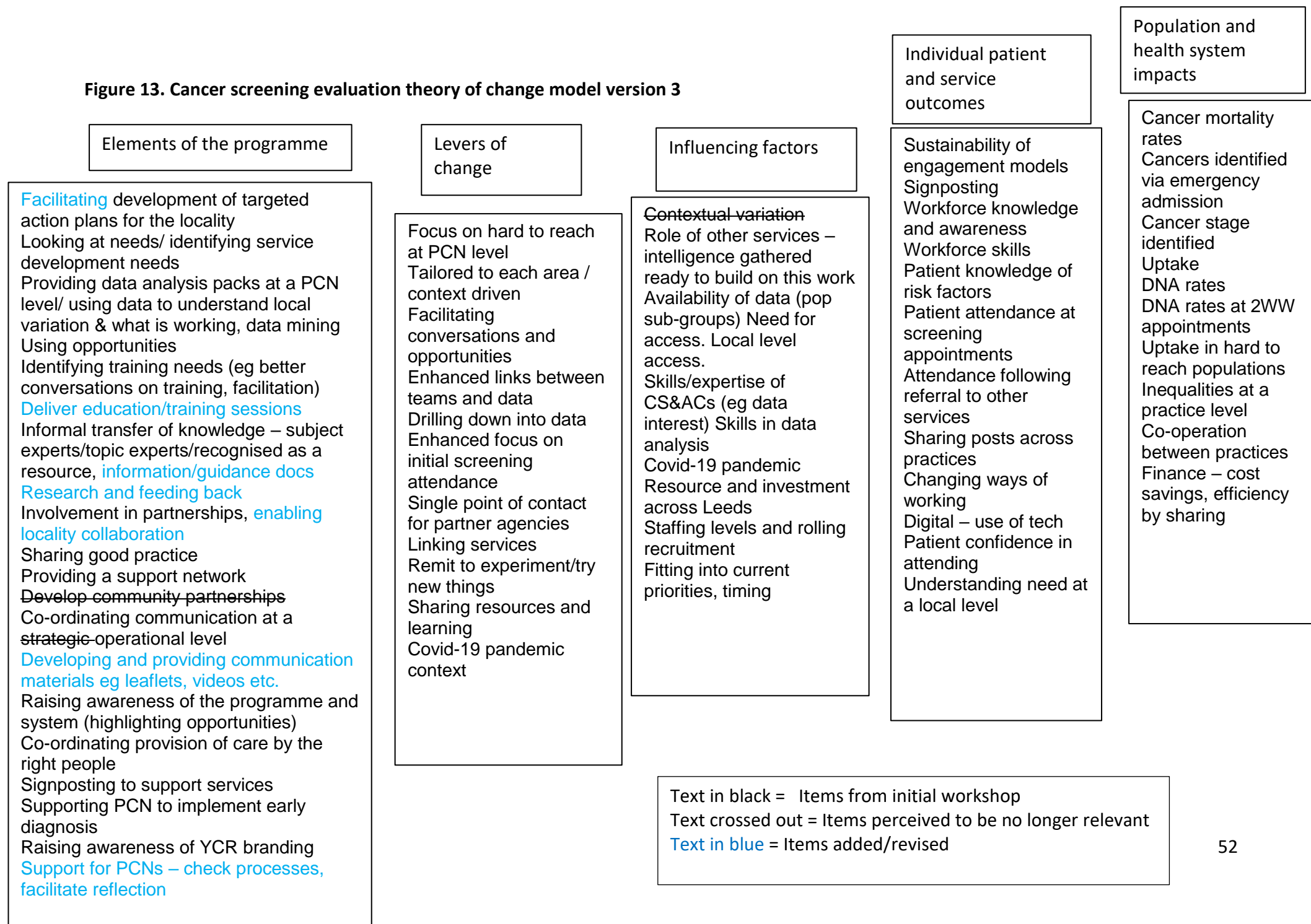
Providing resources

Supporting early diagnosis as part of peer review inc identifying hard to reach pts

Linking with PC development team and champions, attending meetings, providing data, collating reports, provide info and resources

Elements described in this workshop were added to the latest version of the logic model (Figure 13), these are indicated in blue text.

Figure 13. Cancer screening evaluation theory of change model version 3



4. Information from national cancer screening programme measures

Below we present descriptive statistics based on national cancer screening programme data published by Public Health England (PHE)^{1,2} and NHS Digital³. These data are quality assured and recorded in a consistent fashion across England.

COVID-19 and the production of statistics

Disruption from the coronavirus illness (COVID-19) has affected the quality and completeness of published cancer screening statistics from April 2020 onwards. The overall effect on coverage statistics will be limited, as coverage represents a summary of activity over a longer time period.

Data which includes the COVID-19 period should be interpreted with care.

Closure of Public Health England (PHE)

PHE ceased to exist on 1st October 2021. Responsibility for the production of screening statistics has passed to [NHS England and Improvement \(NHSEI\)](#) and [NHS Digital](#). Some statistics will be published by the [Department for Health and Social Care's Office for Health Improvement & Disparities](#) in addition to those bodies.

Measures, frequency and lag

Publicly available sub-national measures for the English cancer screening programmes are limited. There is no disaggregation by characteristics of the target screening populations (other than the 25-49 and 50-64 age split for the cervical screening programme).

A measure of coverage is available for each of the screening programmes. Coverage represents the ability of a screening programme to reach its target population over its target period (varying between 2.5 and 5.5 years). Coverage is a lagged measure as it takes account of participation some years previously.

A measure of uptake is available for the breast and bowel screening programmes, but not for the cervical cancer screening programme. Uptake represents a measure of short-term (6 month) invitee engagement with the screening programme. It does not suffer from the lag associated with coverage.

The frequency of publication of cancer screening measures varies. Coverage and uptake measures for sub-national geographies are mainly published on an annual basis. Measures for the bowel (at CCG level) and cervical (at GP practice, PCN and CCG levels) cancer screening programmes are additionally reported on a quarterly basis for more recent periods.

The lag between the end of the reporting period and the publication of statistics varies considerably by cancer screening programme and appears to be in a state of flux, likely due to the COVID-19 pandemic and recent organisational restructuring.

Presented analyses

We present descriptive analysis and data visualisations of nationally reported screening measures. We believe it is unlikely that a robust interrupted time-series comparative analysis would deliver results achieving "statistical significance" due to limitations in the data available, including the impact of the COVID-19 pandemic. A controlled before-after design would also have considerable limitations due to local variation in underlying long and short term trends.

Comparison between Leeds and similar areas

For the Leeds-level comparisons we present data for NHS Leeds CCG where available. Where data are only available for Leeds City Council we have used this instead. The Leeds City Council and NHS Leeds CCG boundaries are coterminous. However, screening measures at the CCG-level relate to patients registered at GP practices within CCG boundaries; measures at local authority (LA)-level relate to patients resident within that LA boundary (based on their postcode).

Comparison areas were selected using,

- CCGs: NHS England's Similar 10 CCG Explorer Tool⁴: due to CCG mergers since 2018 only 6 comparator CCGs remain for NHS Leeds CCG.
- LAs: CIPFA's Nearest Neighbours Model⁵: The "nearest" 10 comparator LAs were selected.

Comparators are broadly, selected on similarity of demographic profiles (particularly age and ethnicity), population density, and deprivation measures.

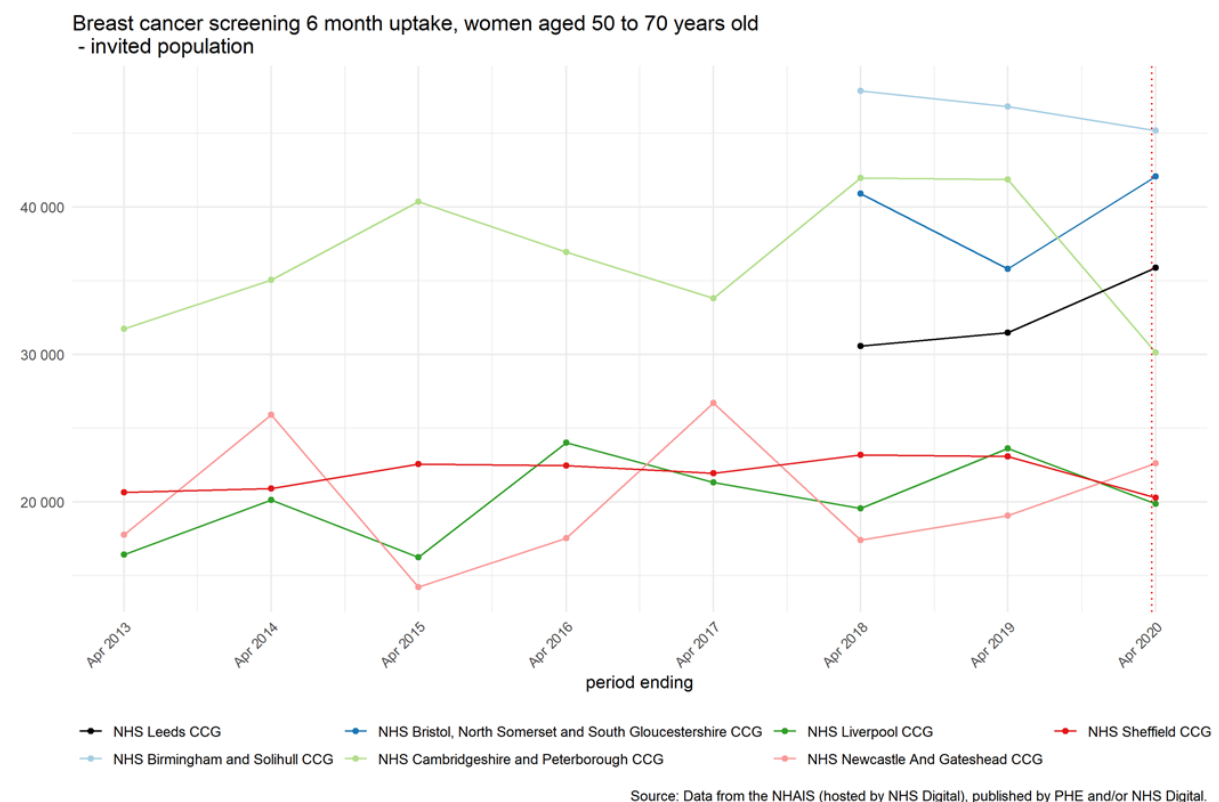
Breast cancer screening

Uptake measures

Leeds CCG's uptake rate is comparable to other similar areas, based on the available data. It is not appropriate to interpret a trend based on only three (annual) data points, other similar areas have a long-term slowly decreasing uptake rate.

An error with PHE's data processing means data for CCGs formed due to mergers in April 2018 (including NHS Leeds CCG) are not currently available for the period before April 2018. This error is due to be corrected later in 2021.

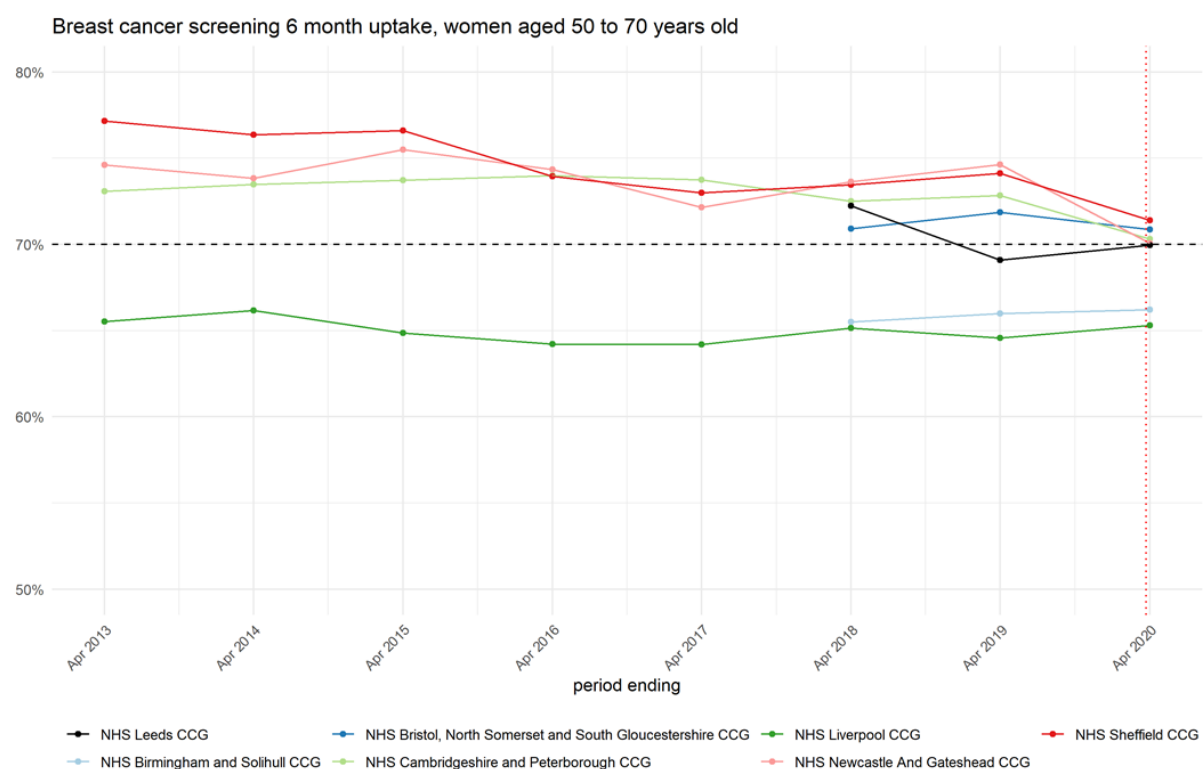
Invited population



Definition: The total number of persons aged 50-70 invited for screening in the 12 months prior to the indicated date. The NHS Breast screening programme only routinely issues invitations to persons registered with a NHS GP as female.

Uptake

The national “acceptable level” is defined as 70.0% or greater for this measure.

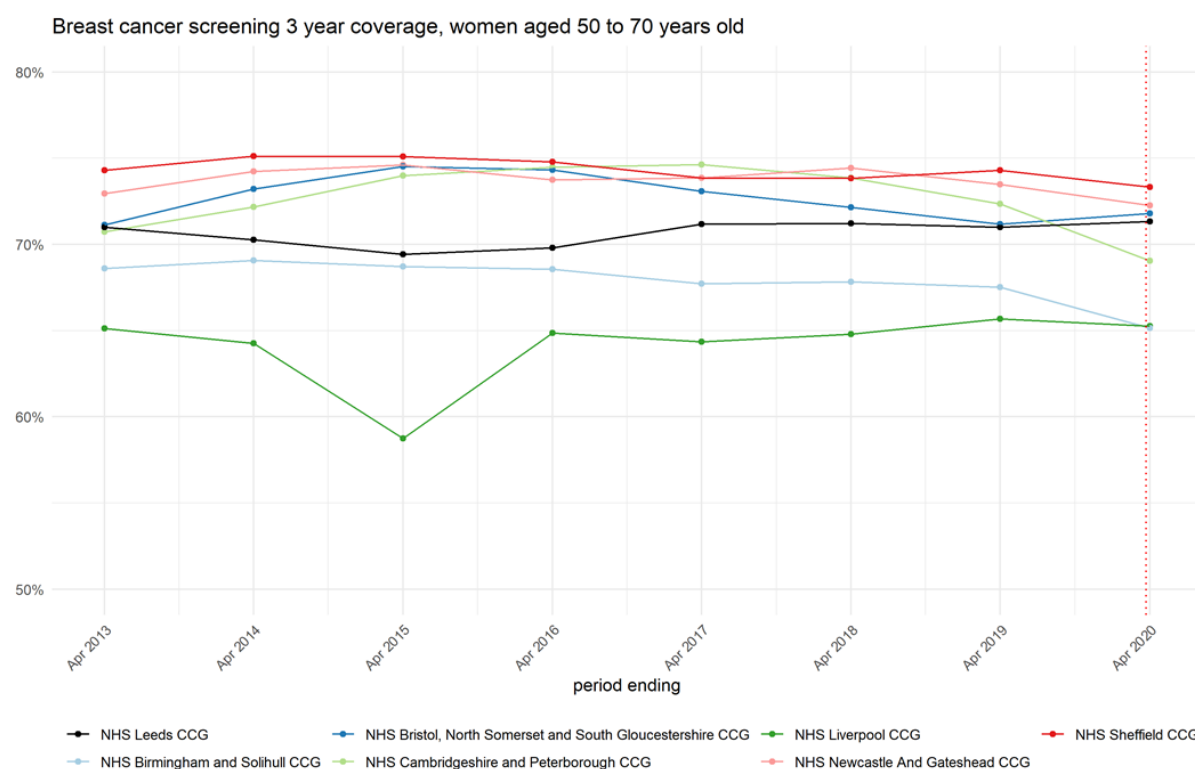


Definition: The percentage of the total number of persons aged 50-70 invited for screening in the 12 months prior to the indicated date who were screened within 6 months of invitation. The NHS Breast screening programme only routinely issues invitations to persons registered with a NHS GP as female.

Coverage

Leeds CCG's coverage rate is comparable to other similar areas. Leeds CCG's coverage rate appears stable over the long-term; similar areas have a stable or long-term slowly decreasing coverage rate.

Data at CCG level are only available for those aged 50 to 70; the national "acceptable level" is based on the cohort aged **53** to 70. Thus, no national "acceptable level" is displayed for this measure.



Definition: The percentage of the total number of eligible persons aged 50-70 on the indicated date who were adequately screened in the 36 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

Bowel cancer screening

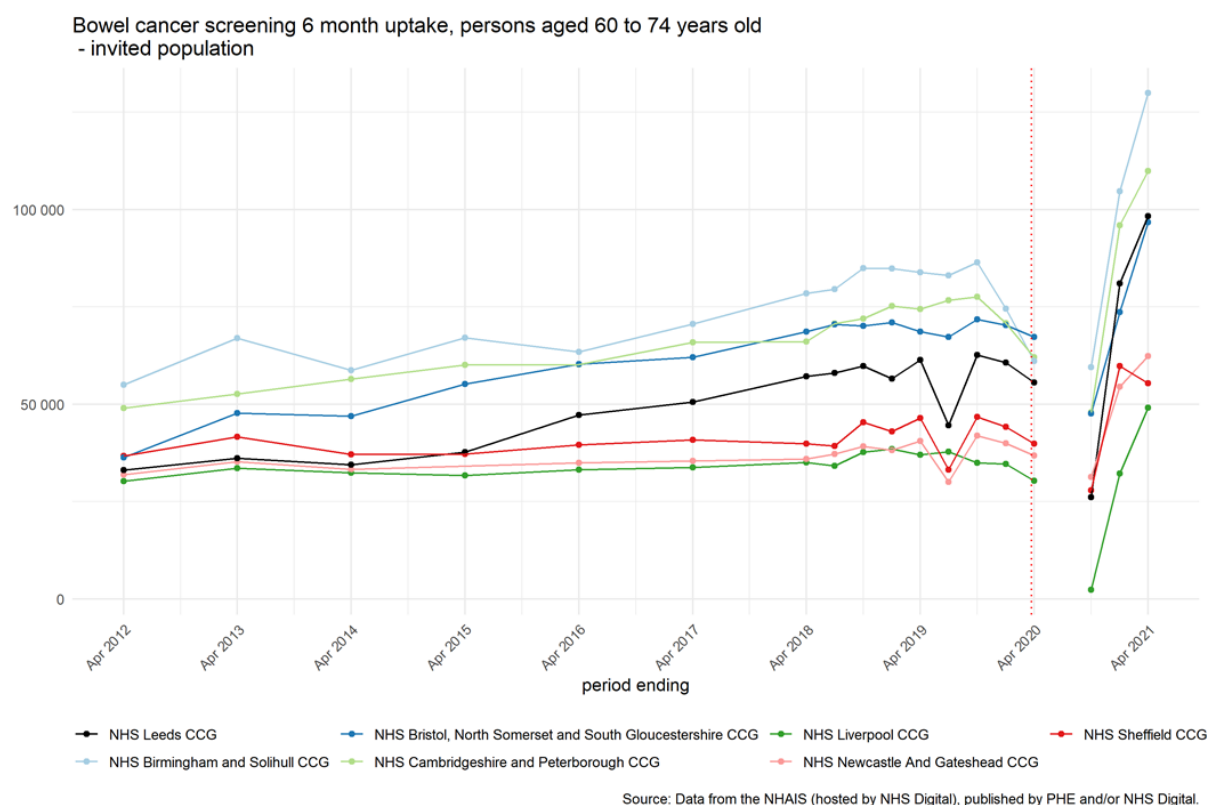
In June 2019 the bowel cancer screening test used in England changed from the guaiac faecal occult blood test (gFOBT) to the faecal immunochemical test (FIT)⁶. In a 2014 pilot study to establish the acceptability and diagnostic performance of the FIT in England, overall uptake increased by over 7% with FIT and uptake by previous non-responders almost doubled⁷.

Uptake measures

Leeds CCG's uptake rate is comparable to other similar areas, toward the better performing side of the range. Leeds CCG has had a long-term increasing trend in uptake which is more linear but comparable to other similar areas. An additional increase in uptake rate in 2019/20 Q2 and maintained after the COVID-19 interruption, across all CCGs shown, can likely be attributed to the introduction of FIT (see under [Bowel cancer screening](#)).

Data for 2020/21 Quarter 1 (Q1, period end 30th June 2020) were withdrawn for this measure because of issues with data quality due to the impact of the COVID-19 pandemic on screening services.

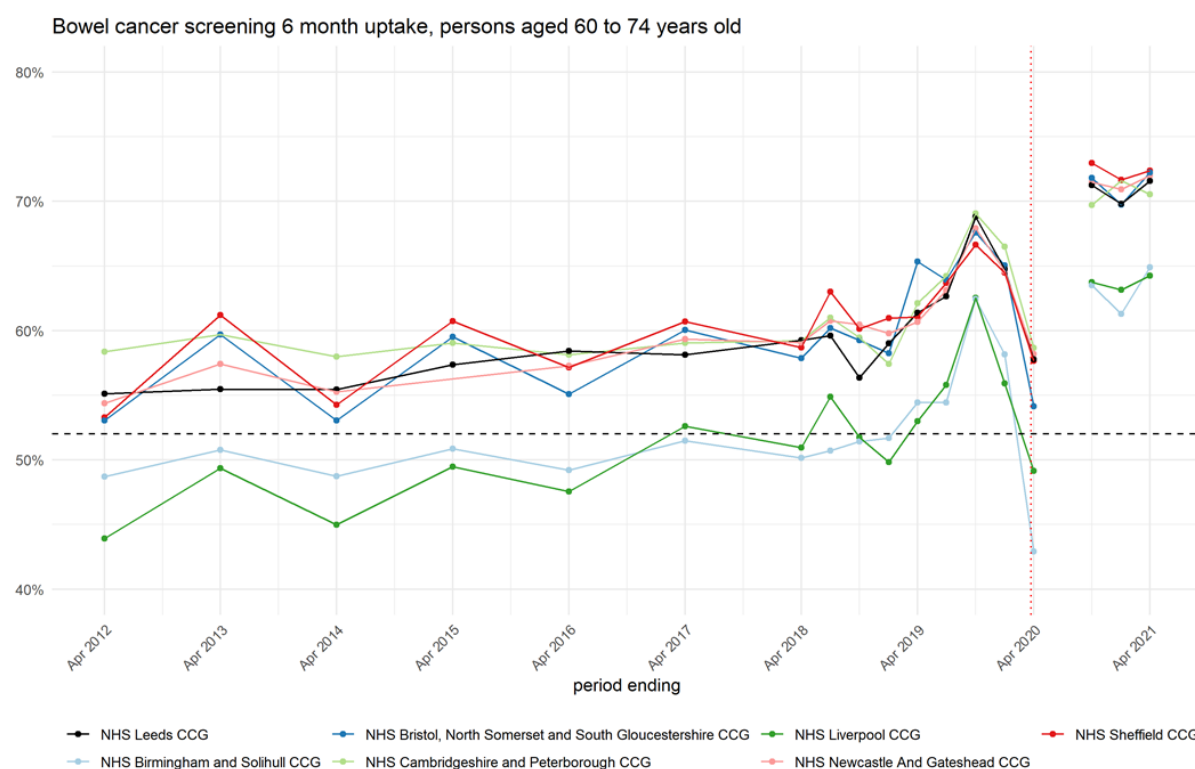
Invited population



Definition: The total number of persons aged 60-74 invited for screening in the 12 months prior to the indicated date. The NHS Bowel cancer screening programme only routinely issues invitations to persons registered with a NHS GP.

Uptake

The national “acceptable level” is defined as 52.0% or greater for this measure.



Definition: The percentage of the total number of persons aged 60-74 invited for screening in the 12 months prior to the indicated date who were screened within 6 months of invitation. The NHS Bowel cancer screening programme only routinely issues invitations to persons registered with a NHS GP.

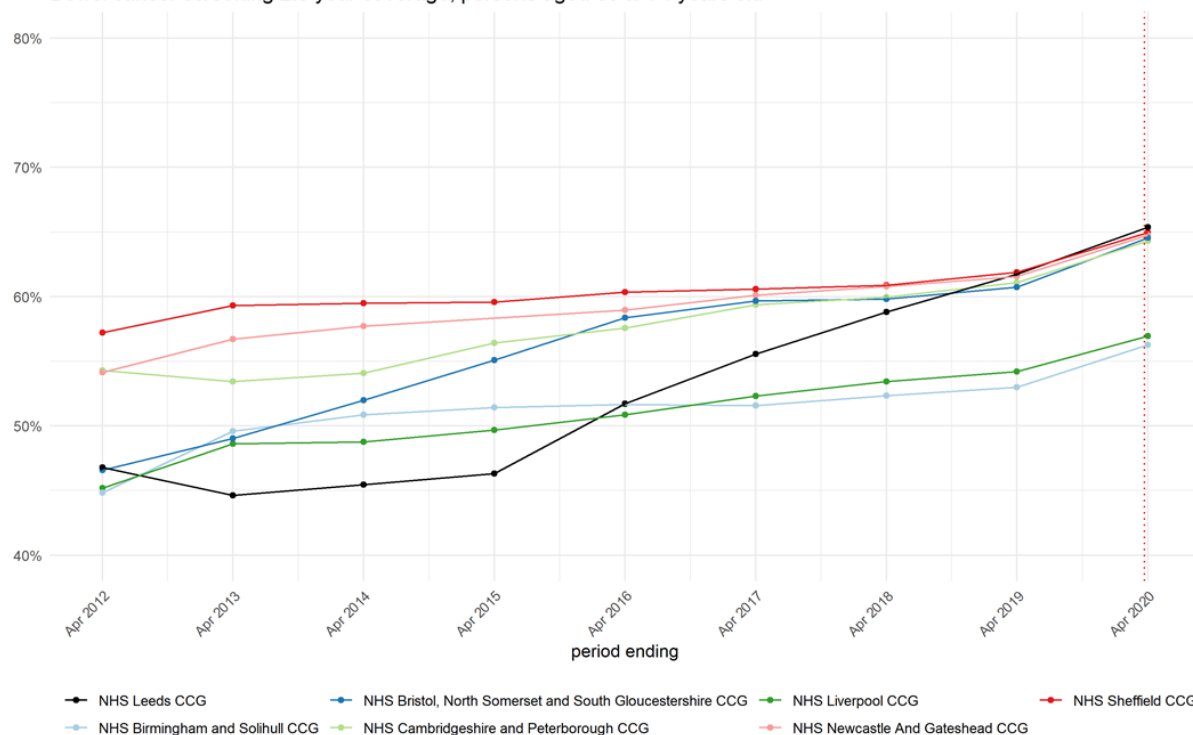
Coverage

Leeds's coverage rate is toward the best of similar areas. Leeds has had a long-term increasing trend in coverage (due to a similar trend in uptake since at least 2012) which has improved Leeds's position from lowest coverage amongst the identified similar areas to amongst the highest coverage between 2015 and 2020. As seen from the LA measure, all areas were broadly similarly, negatively, impacted by the COVID-19 pandemic.

There is no nationally set "acceptable level" defined for this measure.

Data at CCG level are only available annually and only after considerable publication delay.

Bowel cancer screening 2.5 year coverage, persons aged 60 to 74 years old

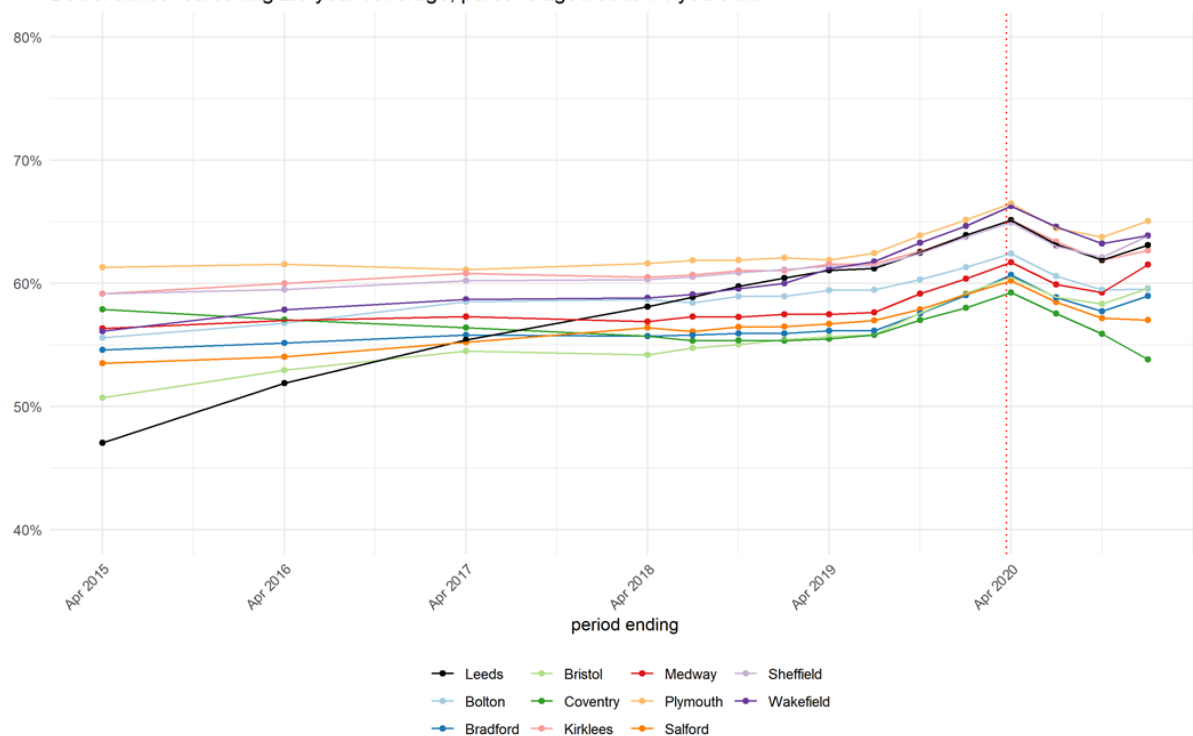


Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

Definition: The percentage of the total number of eligible persons aged 60-74 on the indicated date who were adequately screened in the 30 months prior to the indicated date. Only persons registered with a NHS GP (as at the indicated date) are included in this published data.

However, LA level data are published quarterly.

Bowel cancer screening 2.5 year coverage, persons aged 60 to 74 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

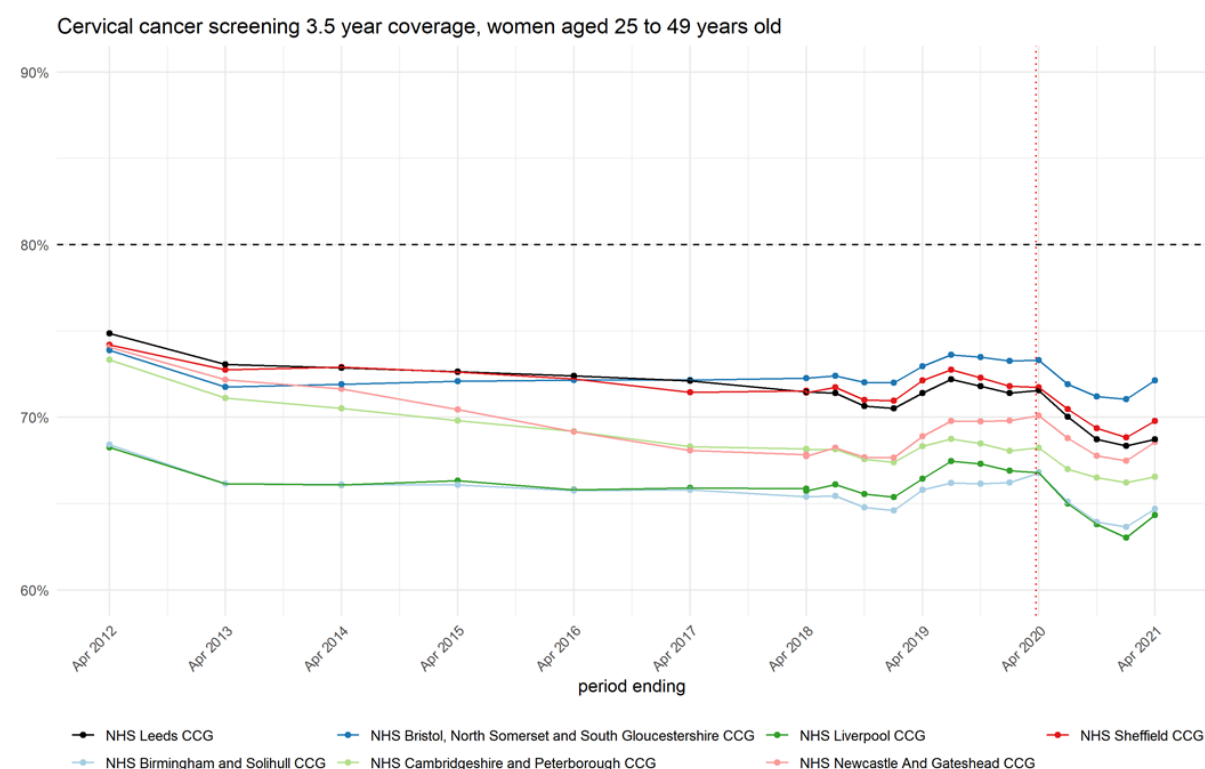
Definition: The percentage of the total number of eligible persons aged 60-74 on the indicated date who were adequately screened in the 30 months prior to the indicated date. Only persons registered with a NHS GP (as at the indicated date) are included in this published data.

Cervical cancer screening

Leeds CCG's coverage rate is toward the best of similar areas. However, Leeds and similar areas have had a long-term decreasing trend in coverage since at least 2012. Leeds CCG's decline in coverage may be slightly greater than some of the identified similar areas but is comparable overall. The longer screening target period for those aged 50 to 64 years compared to those aged 25-49 years (5.5 vs 3.5 years, respectively) means the former measure is less sensitive to recent trends in (unavailable) uptake rates.

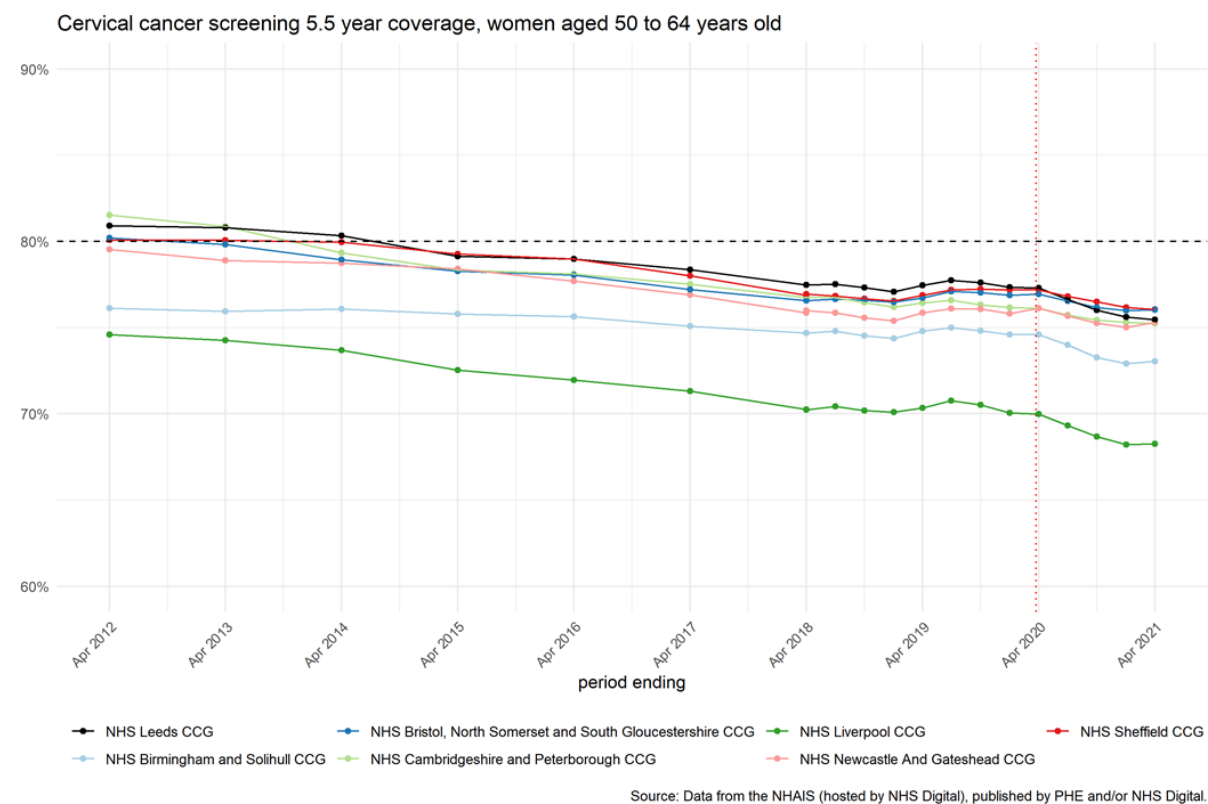
The national cervical cancer screening programme only publishes coverage measures, no uptake measures are available. The national "acceptable level" is defined as 80.0% or greater for both coverage measures.

25 to 49 years



Definition: The percentage of the total number of eligible persons aged 25-49 on the indicated date who were adequately screened in the 42 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

50 to 64 years



Definition: The percentage of the total number of eligible persons aged 50-64 on the indicated date who were adequately screened in the 66 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

Comparison within Leeds between Primary Care Networks (PCNs)

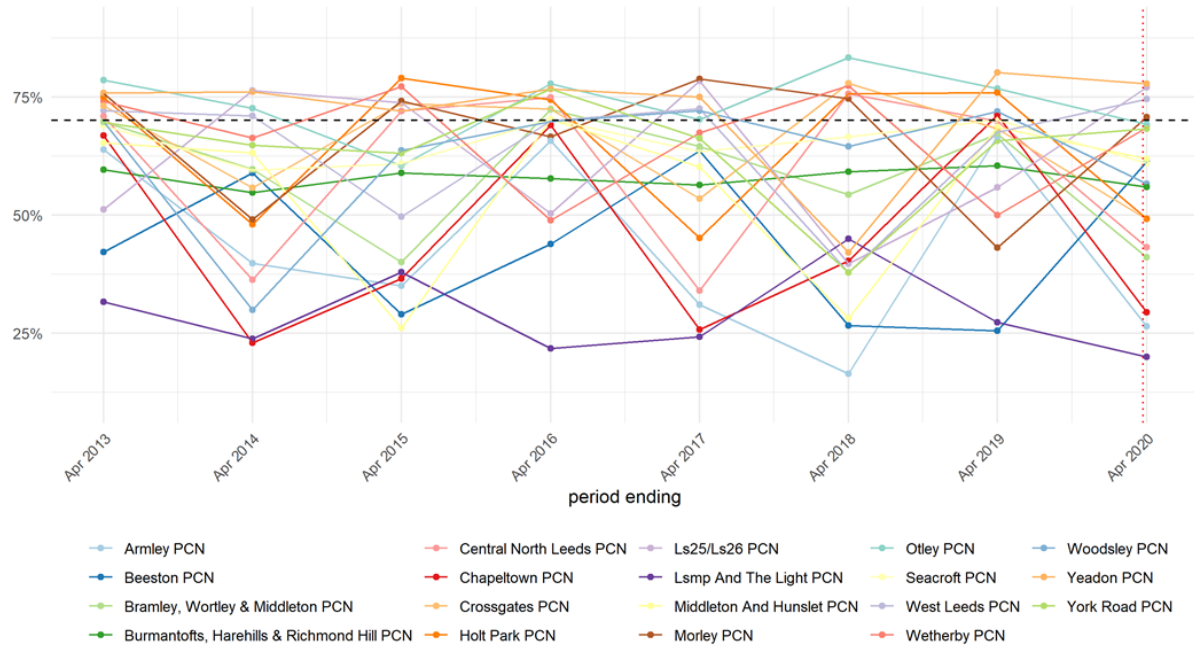
Breast cancer screening

Uptake

There is wide variation in uptake rates between Leeds CCG PCNs, approximately 20% to 80%. There is no strong evidence that this wide range in uptake has changed (narrowed or widened) over time. PCN rank order (relative performance) is variable from year to year but, broadly, PCNs with greater uptake continue to have greater uptake and those with lower uptake continue to have lower uptake.

The national “acceptable level” is defined as 70.0% or greater for this measure.

Breast cancer screening 6 month uptake, women aged 50 to 70 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

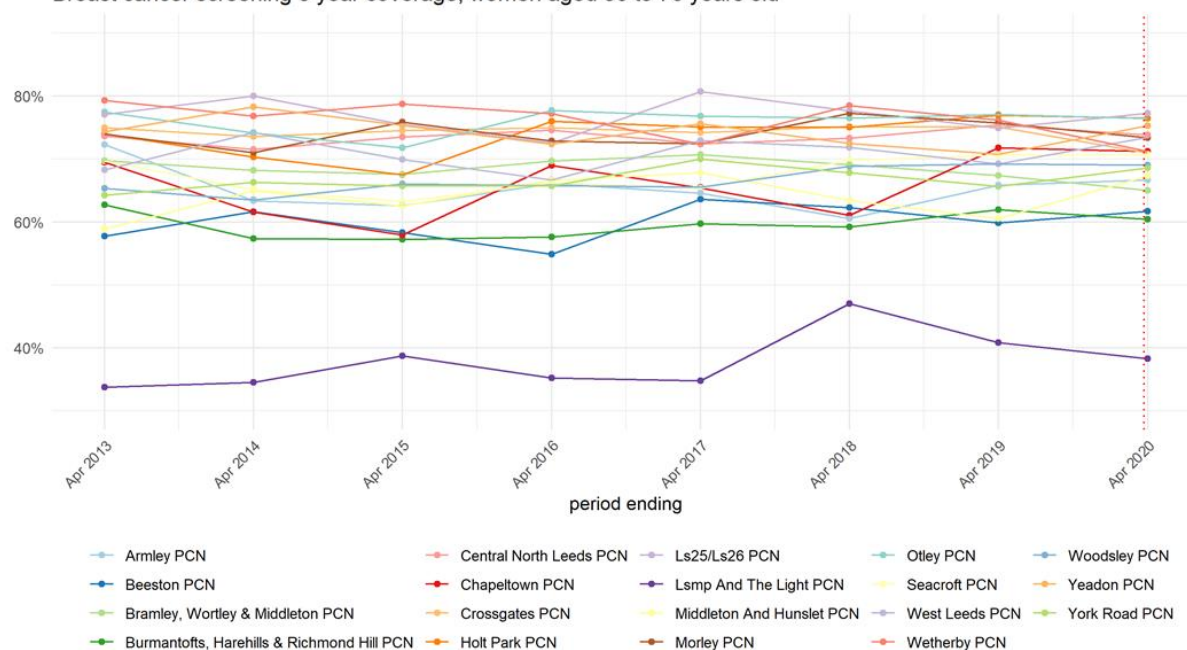
Definition: The percentage of the total number of persons aged 50-70 invited for screening in the 12 months prior to the indicated date who were screened within 6 months of invitation. The NHS Breast screening programme only routinely issues invitations to persons registered with a NHS GP as female.

Coverage

There is wide variation in coverage rates between Leeds CCG PCNs, approximately 38% to 78%. There is weak evidence that this range has narrowed over time however this in the context of broadly stable coverage. This suggests coverage may have increased for lower performing PCNs but may have decreased amongst higher performing PCNs. PCN rank order (relative performance) is variable from year to year but, broadly, PCNs with greater coverage continue to have greater coverage and those with lower coverage continue to have lower coverage.

Data at PCN level are only available for those aged 50 to 70; the national “acceptable level” is based on the cohort aged 53 to 70. Thus, no national “acceptable level” is displayed for this measure.

Breast cancer screening 3 year coverage, women aged 50 to 70 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

Definition: The percentage of the total number of eligible persons aged 50-70 on the indicated date who were adequately screened in the 36 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

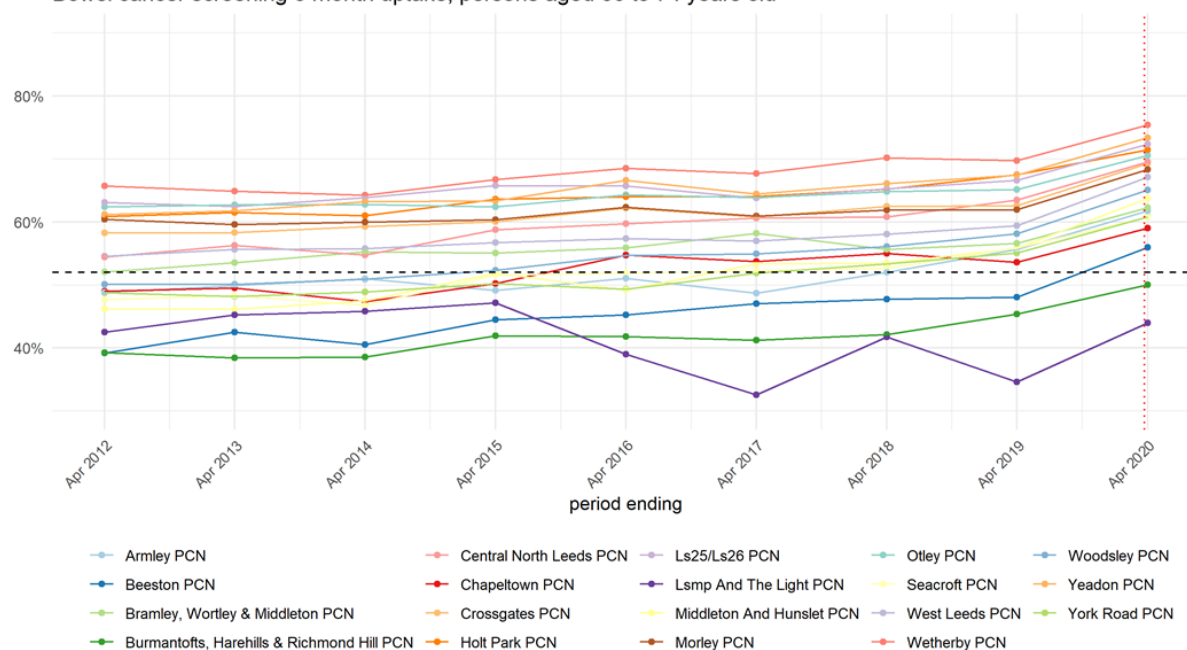
Bowel cancer screening

Uptake

There is considerable variation in uptake rates between Leeds CCG PCNs, approximately 45% to 75%. In the context of almost universal increasing uptake across PCNs, this plot provides some evidence that the range has widened over time. PCN rank order (relative performance) remains broadly similar from year to year, PCNs with greater uptake continue to have greater uptake and those with lower uptake continue to have lower uptake.

The national “acceptable level” is defined as 52.0% or greater for this measure.

Bowel cancer screening 6 month uptake, persons aged 60 to 74 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

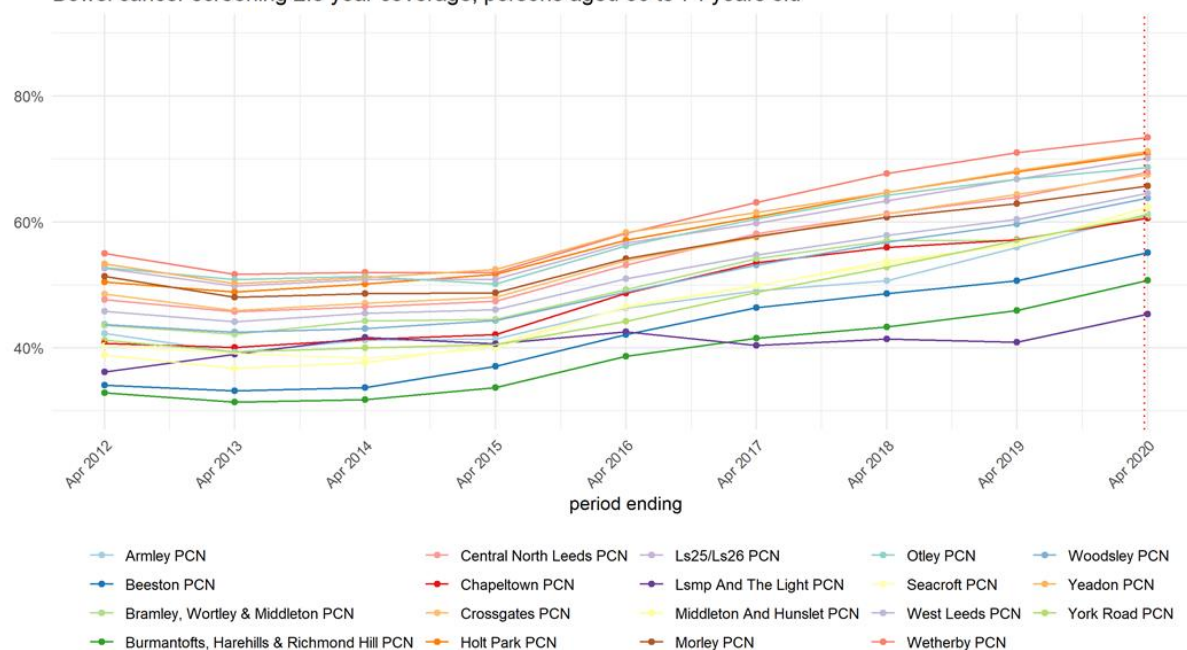
Definition: The percentage of the total number of persons aged 60-74 invited for screening in the 12 months prior to the indicated date who were screened within 6 months of invitation. The NHS Bowel cancer screening programme only routinely issues invitations to persons registered with a NHS GP.

Coverage

There is considerable variation in coverage between Leeds CCG PCNs, approximately 45% to 75%. This plot provides some evidence that this range has widened over time. PCN rank order (relative performance) remains broadly similar from year to year, PCNs with greater coverage continue to have greater coverage and those with lower coverage continue to have lower coverage.

There is no nationally set “acceptable level” defined for this measure.

Bowel cancer screening 2.5 year coverage, persons aged 60 to 74 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

Definition: The percentage of the total number of eligible persons aged 60-74 on the indicated date who were adequately screened in the 30 months prior to the indicated date. Only persons registered with a NHS GP (as at the indicated date) are included in this published data.

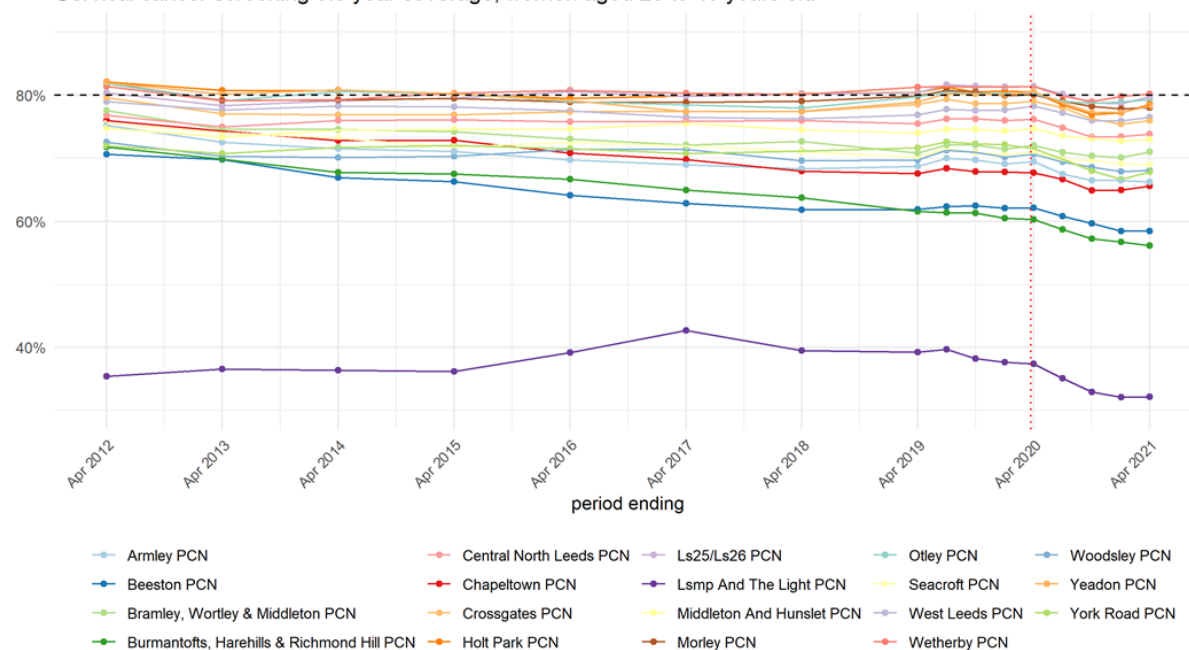
Cervical cancer screening

There is considerable variation in coverage between Leeds CCG PCNs, in both the 25-49 age group (approximately 32% to 80%) and the 50-64 age group (55% to 80%). There is some evidence that this range has widened over time, in the context of overall decline coverage rates. PCN rank order (relative performance) remains broadly similar from year to year, PCNs with greater coverage continue to have greater coverage and those with lower coverage continue to have lower coverage.

The national “acceptable level” is defined as 80.0% or greater for both coverage measures.

25 to 49 years

Cervical cancer screening 3.5 year coverage, women aged 25 to 49 years old

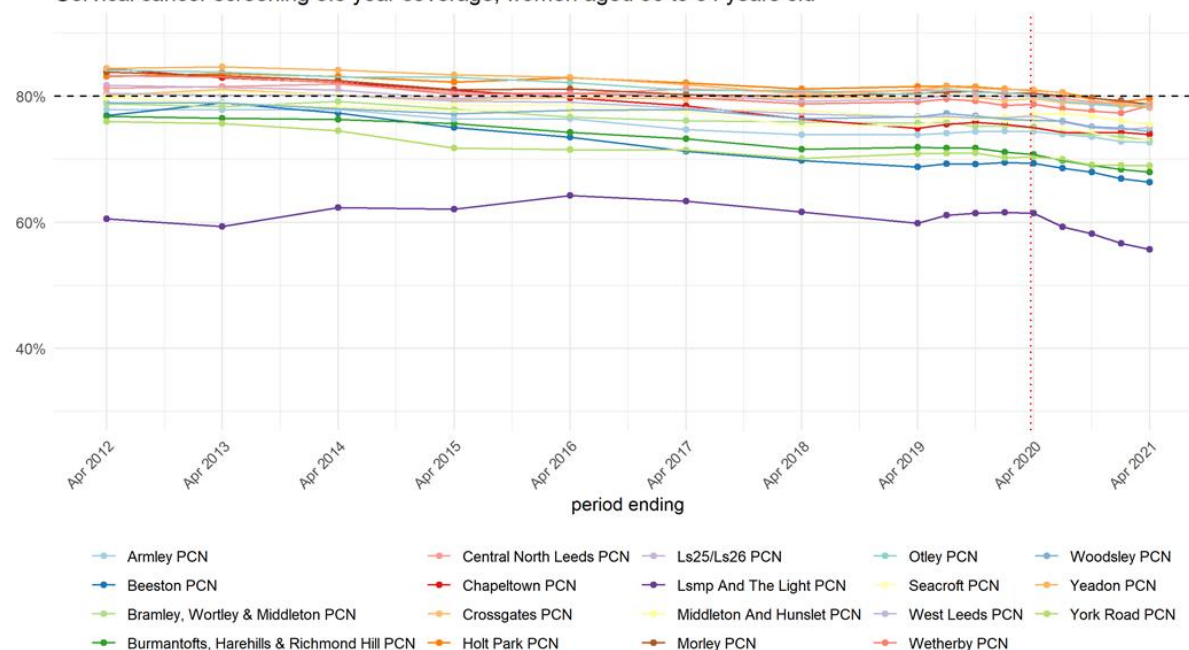


Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

Definition: The percentage of the total number of eligible persons aged 25-49 on the indicated date who were adequately screened in the 42 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

50 to 64 years

Cervical cancer screening 5.5 year coverage, women aged 50 to 64 years old



Source: Data from the NHAIS (hosted by NHS Digital), published by PHE and/or NHS Digital.

Definition: The percentage of the total number of eligible persons aged 50-64 on the indicated date who were adequately screened in the 66 months prior to the indicated date. Only persons registered with a NHS GP as female (as at the indicated date) are included in this published data.

Data sources

Screening Programme	Measure(s)	Organisational / Geographic level	Publication frequency	Source (see references)
Breast	Invited population / Uptake	CCG	Annual	1
Breast	Coverage	CCG	Annual	1
Bowel	Invited population / Uptake	CCG	Annual	1
Bowel	Invited population / Uptake	CCG	Quarterly	2
Bowel	Coverage	CCG	Annual	1
Bowel	Coverage	Local Authority	Annual	1
Bowel	Coverage	Local Authority	Quarterly	2
Cervical	Coverage	CCG	Annual	1
Cervical	Coverage	CCG	Quarterly	3
Breast	Invited population / Uptake	PCN	Annual	1
Breast	Coverage	PCN	Annual	1
Bowel	Invited population / Uptake	PCN	Annual	1
Bowel	Coverage	PCN	Annual	1
Cervical	Coverage	PCN	Annual	1
Cervical	Coverage	PCN	Quarterly	3

References

¹ Public Health England data. Public Health Profiles. 2021 <https://fingertips.phe.org.uk> © Crown copyright 2021. (Accessed 2021-10-21.) Made available under the [Open Government Licence](#).

² Public Health England data. PHE Screening NHS population screening programmes: KPI reports. 2021 <https://www.gov.uk/government/collections/nhs-population-screening-programmes-kpi-reports> © Crown copyright 2021. (Accessed 2021-10-21.) Made available under the [Open Government Licence](#).

³ NHS Digital data. Cervical Screening (Quarterly). 2021 <https://digital.nhs.uk/data-and-information/publications/statistical/cervical-screening-programme> © 2021 NHS Digital. (Accessed 2021-10-21.) Made available under the [Open Government Licence](#).

⁴ NHS England. Similar 10 CCG Explorer Tool. 2018 <https://www.england.nhs.uk/publication/similar-10-ccg-explorer-tool/> (Accessed 2021-10-21.) Made available under the [Open Government Licence](#).

⁵ The Chartered Institute of Public Finance and Accountancy (CIPFA). Nearest Neighbours Model. 2018 <https://www.cipfastats.net/resources/nearestneighbours/> (Accessed 2021-10-21.) Made available under the [Open Government Licence](#).

⁶ NHS England. Briefing sheet: ROLL OUT OF THE NEW BOWEL CANCER SCREENING TEST – FAECAL IMMUNOCHEMICAL TEST (FIT) BRIEFING FOR GPs. 2019 <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2019/06/fit-gp-briefing-sheet.pdf> (Accessed 2021-10-21.)

⁷ Moss S, Mathews C, Day TJ, et al. Increased uptake and improved outcomes of bowel cancer screening with a faecal immunochemical test: results from a pilot study within the national screening programme in England. [Gut 2017;66:1631-1644](#).

5. Economic Analysis Update

Introduction

In the initial report, economic evidence was presented for each of the three screening programmes; breast, bowel and cervical cancer. We aimed to answer the following seven questions, based on pre-existing evidence from the literature, and in the case of bowel cancer screening, some novel analyses carried out using our model Microsimulation Model in Cancer of the Bowel (MiMiC-Bowel)¹.

1. How does participation in screening and follow-up differ by subgroup (subgroups investigated included sex, socioeconomic quintile, ethnic group and learning disabilities)?
2. Is screening cost-effective and beneficial to health?
3. How do the cost-effectiveness and health benefits of screening differ by subgroup?
4. Is increasing participation in screening and/or follow-up cost-effective?
5. How does cost-effectiveness of increasing participation in screening and/or follow-up differ by subgroup?
6. Which interventions are cost-effective for increasing participation?
7. Which interventions are cost-effective for increasing participation by subgroup?

Originally, the interim report should have included an initial economic analysis of the first half of the CS&AC programme. However, screening was disrupted due to COVID-19 and as a consequence there have been problems in both accessing data, and in meaningful interpretation of the existing data given the consequences that COVID-19 has had on screening participation. Furthermore, in responding to the impact of the COVID-19 pandemic on the national cancer screening programmes and the Yorkshire Cancer Research, Cancer Wise Leeds programme, the Programme Governance Group are in the process of reviewing and redefining the objectives of the Programme and the KPIs proposed for use in the management of the programme. In line with these Programme amendments, we have produced a 'minimum effect analysis' in which we present the minimal increase in coverage that is required as a consequence of the CS&AC programme, for the programme to be considered cost-effective given the projected budget spend.

Workshop 11 found that very little CS&AC activity had related to breast cancer so far, no more than 5% of the total, in part arising from the high level of disruption experienced by this screening programme due to COVID-19. The economic analysis therefore focuses on bowel and cervical cancer.

Here we present the methods and results of this ‘minimum effect analysis’ for bowel and cervical cancers, together with a discussion of the findings in the context of the revised KPIs. We make recommendations for KPI coverage targets that should be set to ensure that the CS&AC programme is cost-effective.

Methods

Budget Estimates

The first step was to determine how much of the budget had been spent on each of the cancer screening pathways, and how much of the projected budget for next year would be spent on each of the cancer screening pathways. Workshop 11 asked CS&ACs what proportion of their time they felt they had spent working on improving uptake for each of breast, bowel and cervical cancer, and whether they thought this would change over the next year (remaining programme duration – see chapter 3 for further details). The subjective assessment of the screening coordinators involved in Workshop 11 was that over the first 2.5 years of the programme, approximately 70% of their time had been spent on cervical cancer, 25% on bowel cancer and only 5% on breast cancer. The coordinators thought that over the final year of the programme, the proportion spent on breast cancer would go up to 15%, with the proportion spent on each of the other two cancers reducing to 65% for cervical and 20% for bowel.

Yorkshire Cancer Research revised budget projections estimate that by the end of September 2021, a total of £522,571.93 had been spent on the programme, with a total of £1,037,833.64 estimated to be spent by the end of the programme in September 2022. From these values, estimated budgets for each of the three cancer pathways up until September 2021 and September 2022 (end of CS&AC programme) could be estimated (Table 1).

Table 1: Activity and budget estimates for CS&AC work on the three cancer screening pathways.

Total Budget		Cervical Cancer		Bowel Cancer		Breast Cancer	
		Activity	Budget	Activity	Budget	Activity	Budget
From start to September 2021	£522,572	70%	£365,800	25%	£130,643	5%	£26,129
September 2021 to September 2022	£515,262	65%	£334,920	20%	£103,052	15%	£77,289
Total	£1,037,834	68%	£700,720	23%	£233,695	10%	£103,418

Maximum Cost of Intervention

The next step was to calculate the maximum amount that could be spent on an intervention to get someone to participate in screening who wouldn't otherwise have done so, whilst still remaining cost-effective. This was based upon the cost-effectiveness results presented in the initial report.

For cervical cancer, the initial report included results from a meta-analysis of cost-effectiveness studies ², which reported an estimated increase in lifetime costs of £234 and lifetime QALYs of 0.043 for a woman participating in screening compared to a woman who

does not participate ³. The incremental net monetary benefit of screening can then be calculated as follows:

$$\text{Inc. Net Monetary Benefit} = (\text{Inc. QALYs} * \text{Value of a QALY}) - \text{Inc. Costs}$$

In the UK NICE specifies that the cost effectiveness acceptability threshold, or value of a QALY is typically between £20,000 to £30,000 ³. Using the £20,000 value gives an incremental net monetary benefit of £626.29, whereas using the £30,000 value gives an incremental net monetary benefit of £1,056.29.

For cervical cancer screening the incremental net monetary benefit is equivalent to the maximum amount that could be spent on an intervention to ensure participation in screening by a woman or person with a cervix who wouldn't previously have participated in screening. Given that those who are eligible for cervical screening are invited to cervical screening multiple times (a total of 12 invites; 9 three-yearly invites between the ages of 25 and 49, and a further 3 invites to five-yearly screening between the ages of 50 and 64), and on average attend 8.7 screening invitations (assuming 71% participation for three-yearly screening and 77% participation for five-yearly screening based on PHE Fingertips data⁴), we made the assumption that this screening benefit is evenly spread between the screening invitations in which individuals participated. This resulted in a maximum cost that could be spent ensuring an eligible person participated in a particular screening invite who would not otherwise have participated of £72 at the £20,000 value of a QALY and £122 at the £30,000 value of a QALY.

For bowel cancer screening, in the initial report we had already estimated the maximum amount that could be spent to get someone to participate in faecal immunochemical testing (FIT) who wouldn't otherwise have done so ⁴. The initial report indicates that the maximum cost estimates vary by sex, socioeconomic deprivation and ethnicity; however, as it was unclear exactly where CS&AC activity had been focussed, we assumed that participation increases would be spread proportionately through the population and so used the total

³ Also see page 40 of initial report

⁴ Table 7 on page 48 of the initial report

population value of £96, which is based on the £20,000 value of a QALY ⁵. An equivalent calculation at the £30,000 value of a QALY threshold produced an estimate of £146.

Minimum Effect Analysis

The number of additional screening participations required to ensure cost-effectiveness of the cervical and bowel cancer screening elements of the CS&AC programme were calculated using the following formula:

$$\text{Number Additional Participations Required} = \text{Budget Spent} / \text{Maximum Cost of Intervention}$$

A final step was to convert absolute numbers of additional participations in screening required for cost-effectiveness into a proportional increase in coverage based on the KPI coverage targets.

For cervical cancer, revised KPIs approved by Yorkshire Cancer Research are to increase cervical screening coverage by 3% from 70.4% (January 2021 baseline) to 73.4% (September 2022). This is anticipated to be an increase of 4608 additional people screened from the January 2021 baseline to the programme end point in September 2022.

For bowel cancer, KPIs are still under revision, but for the purposes of the report the former KPIs were used, which are to increase bowel screening coverage by 5% from 66.5% in February 2020 to 71.5% in September 2022. This is anticipated to be an increase of 2778 additional people screened.

Increase in coverage required to ensure cost-effectiveness was calculated based on these KPI estimates of target % increase in coverage and additional numbers expected to be screened using the following formula:

$$\% \text{ Coverage Increase} = \text{KPI \% Coverage Increase} * \text{Minimum Additional Participations Required} / \text{KPI number additional people expected to be screened}$$

⁵ Table 7 on page 48 of the initial report

Results

Table 2 and Table 3 show results for the cervical and bowel cancer screening pathways respectively. The results suggest that a minimum of 5,076 additional cervical screening participations and 1,361 additional bowel screening participations are required to ensure that the CS&AC programme has been cost-effective (assuming a £20,000 value of a QALY) given the budget spent up until September 2021, and that by the end of the programme this will have increased to a total of 9,724 additional cervical screening participations and 2,434 additional bowel screening participations. This additional participation must be directly attributable to the CS&AC programme and not to other factors that would have occurred anyway without the programme. Note that it is not possible to split the number of additional cervical screening participations required by age group, as data was not available to inform how cost-effectiveness differs by age group.

In terms of screening coverage, the CS&AC programme needs to improve coverage of cervical cancer screening by a minimum of 6.3% (i.e. from 70.4% at the January 2021 baseline to 76.7% by September 2022), and bowel cancer screening by a minimum of 4.4% (i.e. from 66.5% at the February 2020 baseline to 70.9% by September 2022), assuming a £20,000 value of a QALY, to ensure that the programme has been cost-effective. Using a higher value of a QALY reduces the percentage increases required.

Table 2: Calculation of total number of additional cervical screening participations, and the percentage increase in coverage required to ensure that the cervical cancer screening element of the CS&AC programme is cost-effective.

Time Period	Programme Budget (Cervical Cancer)	Value of a QALY	Maximum Cost Additional Cervical Screening Participation	Minimum Number Additional Cervical Screening Participations Required (Total)	% Increase in Cervical Screening Coverage
From start to September 2021	£365,800	£20,000	£72	5,076	3.30%
		£30,000	£122	3,010	1.96%
	£700,720	£20,000	£72	9,724	6.33%

From start to September 2022		£30,000	£122	5,765	3.75%
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Table 3: Calculation of total number of additional FIT participations, and the percentage increase in coverage required to ensure that the bowel cancer screening element of the CS&AC programme is cost-effective.

Time Period	Programme Budget (Bowel Cancer)	Value of a QALY	Maximum Cost Additional FIT Participation	Minimum Number Additional FIT Participations Required (Total)	% Increase in Bowel Screening Coverage
From start to September 2021	£130,643	£20,000	£96	1,361	2.45%
		£30,000	£146	895	1.61%
From start to September 2022	£233,695	£20,000	£96	2,434	4.38%
		£30,000	£146	1,601	2.88%

Discussion and Comparison with KPIs

The findings of this analysis indicate that the CS&AC programme needs to have a significant impact in increasing coverage of screening to ensure that the programme has been a cost-effective use of money. We would suggest setting coverage targets for the end of the programme that are at least 6.3% higher than cervical screening coverage would be expected to be from prior trends or national comparisons, and 4.4% higher than bowel screening coverage would be expected to be. If such targets are not met then it is highly unlikely that the CS&AC programme would be cost-effective at a threshold of £20,000 per QALY gained.

For cervical screening coverage of the two age groups is reported separately (see Chapter 4). At a national level this has been gradually decreasing since 2012. Coverage data is only available for the first two years of the CS&AC programme, but during this time the trends in Leeds do not appear to diverge significantly from those in other similar CCGs. Note however,

that as data only goes up to April 2021, as yet there is insufficient data to make a fair comparison. Agreed revised target KPIs for cervical screening coverage are aiming for a 3% increase. The cost-effectiveness estimates presented here indicate that this is insufficient to ensure that the cervical part of the CS&AC programme will be cost-effective and that instead targets of a minimum of 6.3% should be set.

For bowel cancer screening, coverage started increasing significantly from 2019 when FIT screening was introduced and uptake of bowel cancer screening increased sharply (see Chapter 4). This increase in uptake is due to the nature of the FIT which only requires a single sample rather than three consecutive samples to be taken, and was predicted by the FIT pilot⁴. The consequence of this increase in uptake is that coverage is expected to have continued increasing for over 2 years from the end of 2019 as gradually the entire screening population is invited to their first FIT. This gradual, expected increase complicates the coverage data and makes it difficult to disentangle increases in coverage due to the change to FIT and increases in coverage due to other reasons (such as the CS&AC programme). Bowel cancer screening was completely disrupted for three months during COVID-19, so reliable coverage data is only available prior to early 2020. As yet, it is therefore unclear whether the trends in Leeds differ significantly from those elsewhere in the country, although this may become apparent when further data is released. Target KPIs for bowel screening coverage are as yet still under discussion, but proposed targets are aiming for a 5% increase. Assuming that this KPI is based on increases over and above those expected throughout England due to the change to FIT screening, the cost-effectiveness estimates presented here indicate that this is sufficient to ensure that the bowel part of the CS&AC programme will be cost-effective.

In workshop 11, CS&ACs indicated that many of the activities that they are doing could have impacts that last well beyond the end of the programme. If this is the case, then lower percentage increases in coverage might be cost-effective if they persist beyond the programme end. In this case the minimum total number of additional participations required to ensure cost-effectiveness should be used as a guide to assess at what point coverage increases have resulted in sufficient additional screening participation. However, as this goes beyond the period of analysis it is unclear how longer term benefits might be assessed.

Longer term benefits in terms of increased coverage for a longer duration might also be obtained if some CS&AC activity along similar lines to that currently being funded, is funded beyond the end of the programme. This would likely be much cheaper than the programme itself as many of the programme costs are sunk costs spent to set-up the programme, which would not need to be spent again, rather than ongoing operating costs. A similar type of analysis to that done here could be repeated to determine the minimum uptake increase that would be required to make a continuation of one or more CS&AC posts cost-effective.

We have carried out these analyses assuming that the value of a QALY is the same as that used by NICE to assess interventions within the NHS. However, if Yorkshire Cancer Research or Leeds PCN were happy to pay more than the NHS for cancer benefits, then lower increases in uptake than those presented here may still be cost-effective by that metric.

References

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3. Guide to the methods of technology appraisal National Institute of Health and Care Excellence (NICE); 2013. <https://www.nice.org.uk/process/pmg9/resources/guide-to-the-methods-of-technology-appraisal-2013-pdf-2007975843781>
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6. Conclusions and recommendations

Conclusions

1. Qualitative data indicate the benefits of CS&ACs in terms of providing an **increased understanding of the local population**. In particular, our findings highlight the positive effects of CS&ACs carrying out in-depth scrutiny of sub-population data and between-group variance, in order to explore explanations for non-attendance and variations between population groups. This work has been a key element of the role and was not previously possible before introduction of the programme. By better understanding local data, the CS&ACs have been able to recommend ways to better enable and facilitate people to take up screening. The data highlight that each Primary Care Network operates very differently, so a **context driven** approach is required to plan and deliver interventions at a local population level.
2. Qualitative data emphasise the importance of having people **embedded in primary care**, who are perceived to be and are in actuality part of the team. The CS&ACs are seen by many to have the role of experts in cancer screening, and are increasingly well recognised for what they do locally. They are also perceived to have a valuable role in **providing support** on cancer screening to PCNs and individual practices.
3. Positive effects on cancer screening rates are perceived to have occurred as a result of **informal and formal sharing of information and expertise**. Informal routes include the cascading of latest research and up to date local data, and more formal routes have included supporting Cancer Champions by developing and delivering training in collaboration with Cancer Research UK, and cascading and sharing resources...
4. Qualitative data suggest that the CS&ACs have acted as **agents for change**, by taking the lead on local innovations to service delivery (such as out of hours clinics), and being a proactive voice arguing for how things can be done differently. Their role in changing ways of working within and across PCNs has the potential to lead to future cost savings associated with sharing resources in Leeds.
5. The context of the Covid-19 pandemic has been a catalyst for greater **collaborative working** between individual practices and primary care networks, and the CS&ACs have been able to capitalise on these opportunities for sharing innovation and learning. An example of where potential impact may result from their role in

increasing collaboration, has been working with Extended Access to increase the availability of appointments.

6. Results of the economic analysis indicate that over its 3.5 year duration the CS&AC programme needs to improve coverage of **cervical cancer screening by a minimum of 6.3% (an additional 9724 screening participations)** and **bowel cancer screening by a minimum 4.4% (an additional 2434 screening participations)** to ensure that the programme has been cost-effective. Agreed revised target KPIs for cervical screening coverage are aiming for a 3% increase, which is insufficient to ensure that the cervical part of the CS&AC programme will be cost-effective. Target bowel cancer screening KPIs are 5%, which is sufficient to ensure that the bowel cancer part of the CS&AC programme is cost-effective, assuming that increases are over and above those expected throughout England due to the change to FIT screening..

Table summarising current (revised) programme KPIs and recommended minimum KPI targets

	Cervical Cancer	Bowel Cancer
Programme KPI: Actual Numbers Additional Participations	4608	2778
Programme KPI: % Increase in Coverage	3.0%	5.0%
Recommended Minimum KPI Targets: Actual Numbers Additional Participations	9724	2434
Recommended Minimum KPI Targets: % Increase in Coverage	6.3%	4.4%

Recommendations

1. An area where qualitative data indicate improvements could be made relates to **staffing**, and includes the introduction of a more formalised induction process for new CS&ACs, together with having a timely training package in place including instruction on SystmOne and data analysis methods. Staff turnover and staffing generally has been a considerable challenge due to the Covid-19 pandemic however, induction and ongoing support may have a key role in retention. The obstacle of non-NHS pensions, issues around secondment, and a perceived lack of clarity regarding the CS&AC role have also contributed to staffing difficulties.

2. It is suggested that there could be enhanced consistency in the **support** provided to individual CS&ACs, which was reported to be varied. There appears to have been considerable leaning on the existing skills and areas of interest of staff.
3. While there has been a growing recognition of the role of the CS&ACs, there is still work to be done in some quarters to ensure an awareness and **appreciation of the role** from other stakeholders including within PCNs.
4. The value of moving away from a focus on individual practices to more **PCN-wide** activities is recommended to provide opportunities for applications for future funding screening initiatives.
5. There seems to be potential for CS&AC to be a greater embedded part of Extended Access working on **population health management**.
6. The inclusion of the **voluntary sector** in the development of new initiatives is important, so they are able to inform the communities they work in. This seems to be a key area for future further development.
7. It is recommended that **screening coverage KPI targets** are set that are a minimum of 4.4% higher for bowel cancer (an additional 2434 screening participations) and 6.3% higher for cervical cancer (an additional 9724 screening participations), than coverage would be expected to be according to prior trends or national comparisons. Such targets would be required to ensure that the programme will be cost-effective based on current NICE cost effectiveness criteria.

7. Proposed content of the final report

The final report will follow a similar broad chapter structure to this report. It will comprise a summary of the overall evaluation of the programme including findings from the first and interim reports. It will include the qualitative and quantitative economic aspects, including findings from up to six further workshops on perceived effectiveness of the programme from all relevant stakeholders. Subject to available data we will provide an overall evaluation of cost effectiveness including potential deaths avoided for all three cancer screening programmes. This will be discussed with Yorkshire Cancer Research and a plan agreed.