

Report of

**THE INDEPENDENT REVIEW OF ADULT
SCREENING PROGRAMMES**

in England



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FOREWORD

I was originally commissioned to undertake this review following a difficult period for NHS cancer screening, in which two national incidents had been declared. As I published interim findings of a review into the management of cancer screening programmes last May, my terms of reference were significantly extended to include other adult screening programmes. In this context, I would like to start by clarifying the remit of this report.

Screening is a widely used term and encompasses a range of activity. My review has focused on screening programmes which target the adult population and importantly, also require people to be actively called and recalled for screening. Specifically, these are the screening programmes for abdominal aortic aneurysm, bowel cancer, breast cancer, cervical cancer and diabetic eye screening, noting that the latter also extends to young people. Together, these programmes save around 10,000 lives a year through prevention and early diagnosis. As a country, they give us much to be proud of.

It is also true to say however, that they are far from realising their full potential. Numerous issues affect and hinder their functioning and lead to delays in making improvements which are already proven to work. Every day of delay is a missed opportunity to catch a person's cancer or disease at an earlier point, and potentially save their life. The way screening is carried out in the future is also likely to change. New innovations are already on the horizon, including developments in genomics and artificial intelligence. Combined with growing evidence on new approaches for population and targeted screening, these will provide many more opportunities to enhance the quality of people's lives. Urgent change is needed if NHS screening programmes are to have any chance of realising this potential.

In undertaking this review, I have therefore kept a deliberate focus on the future. I have met many people with an interest in screening from government officials and national NHS leaders, through to clinicians, commissioners, service providers and service users. I have liaised with academics and reviewed relevant research and reports, attended committee meetings, and participated in various roundtables and conferences specifically convened for this purpose. I have received further responses through my call for evidence and have had the pleasure of several local visits, speaking to those who are experiencing these issues first hand. I offer my sincere thanks to all who contributed and offered up their time so freely. Your messages came through loud and clear and I have sought through this review to make at least one high level recommendation to address each of the key challenges identified.

The issue of governance, which is so fundamental to enable change and to ensure quality and safety is considered in two parts. First, how should recommendations on population and targeted screening best be made to Ministers? Second, once decisions have been made, how should the effective delivery of these programmes be overseen?

It is widely agreed that recommendations on screening should be made by a body which is independent of the organisation charged with delivery. Given the growing importance of risk stratified or targeted screening, I make a key recommendation that a single advisory body be established, bringing together the current functions of the UK National Screening Committee on population screening and NICE on screening for people at elevated risk of serious conditions.

This body should make recommendations to Ministers in all four countries. In England, it follows that funding decisions on targeted screening should be made by Ministers, supported by the Chief Medical Officer and Chief Scientific Adviser, rather than relying on local commissioning. This would mirror the current approach for population screening.

My second key recommendation is that following decisions by Ministers, oversight of delivery of all aspects of screening should become the responsibility of a single organisation, namely NHS England. While collecting evidence for this report, I have repeatedly been asked: who is in charge of screening? Who is accountable for improving uptake for maintaining IT systems, for preventing and addressing incidents and undertaking quality assurance? What are the benefits of having multiple organisations responsible for these different aspects?

The answer is often not obvious, and the result has been that changes to programmes which would have led to more lives being saved have been slow to be implemented. I have not heard any convincing support for the current split in governance between Public Health England and NHS England.

The governance of quality assurance requires particular consideration. The screening quality assurance teams have important roles in identifying problems within local service providers and in helping to resolve these problems, working closely with commissioning teams and with provider organisations themselves. The current organisational divide between the quality assurance teams, and those responsible for commissioning, does however hamper this close working. I therefore recommend that these teams are brought together within NHS England.

I do, however, recognise the need for the quality assurance teams to have independence in reporting significant issues. I therefore also recommend that quality assurance reports on local services should routinely be published and should be made available to the Care Quality Commission, so that regulatory action can be taken if and when necessary.

Next, my report considers the challenges posed by IT systems that are woefully out of date and long due for replacement. This is critical in the context of programmes which rely so heavily on being able to quickly and accurately identify, invite and manage the screening of those eligible. The recent decision that NHSX should take overall responsibility for replacing these systems is therefore very welcome.

It is widely agreed that IT systems for breast and cervical screening are in the most urgent need of renewal. Since publishing my interim report, the 'discovery' phase for developing these new IT systems is nearing completion, involving extensive interviews with key stakeholders and observation of their current functioning. This has confirmed and amplified the concerns identified through my own review. It has also identified multiple inefficiencies as well as opportunities for error and corresponding benefits that will accrue from a new system.

NHSX, working closely with Public Health England, NHS England and NHS Digital, is already taking forward the initial scoping phase for these programmes before development work commences. It will be important to progress this work programme at pace, and under close scrutiny.

The report then turns to the slow decline in the number of people who take up the offer of screening out of those eligible – also particularly evident in the breast and cervical screening programmes. Whilst this trend is also seen internationally, it must be reversed.

Service organisation has not kept pace with people's expectations for convenience in booking appointments and some groups within society are particularly poorly served. Subject to further evaluation where necessary, interventions which have been shown to be effective in increasing uptake should be universally implemented by all screening providers. This includes the use of social media for example, or the issuing of text reminders to patients. Providers should also be incentivised through tariffs or other measures to provide screening or other services at times which are convenient.

The timeliness of providing results to those screened and of arranging investigations and treatment for those who need it are clearly of great importance both for patient experience and potentially for outcomes. As part of my review, I have therefore also considered indicators which have the greatest impact on patient outcomes to recommend how performance can be further improved.

The recommendations I make in this report are intended to save lives and set an even stronger foundation to support delivery of the commitments set out in the NHS Long Term Plan. They will inevitably carry financial and resourcing implications and will need to be assessed in light of available funding resources. Screening programmes are constrained by the size and nature of their workforce, and the equipment and facilities available to them. They also do not operate in isolation and will often share staff, facilities and equipment with other

NHS services, which are also under pressure. Resourcing and capacity will act as barriers to implementing the recommendations set out in this report unless properly considered and addressed.

The report closes by emphasising the importance of audit and research to monitor progress and identify opportunities to make even further improvements, including potential new screening programmes. The NHS provides an unparalleled platform for such research. Academics however, hit obstacle after obstacle in undertaking this vital activity, largely due to delays in access to screening data. These barriers to research must be minimised, paying due consideration to the need to protect personal data and not interfere with the smooth running of the programmes.

I end by once again expressing my gratitude to the many people who made time to speak to me about their experiences and knowledge of screening programmes, and for being so honest and candid in their views. I also extend my sincere thanks to the secretariat team for the support they have given throughout this review.



A handwritten signature in black ink, which reads "Mike Richards". The signature is written in a cursive, flowing style.

Professor Sir Mike Richards

Chair – Independent Review of Adult Screening Programmes in England

EXECUTIVE SUMMARY

WHAT DO WE MEAN BY SCREENING?

Screening is a widely used term in the NHS and can take various forms, ranging from national population screening programmes (for breast screening for example) through to screening that occurs as part of routine care (a GP screening for high blood pressure). Further detail is set out in Chapter 1.

The primary focus of this review is on screening programmes which target the adult population and require people to be actively called and recalled for screening as required. Specifically, these are the screening programmes for abdominal aortic aneurysm (AAA), bowel cancer, breast cancer, cervical cancer, and diabetic eye screening (DES), noting that the latter also extends to young people from the age of 12.

LOOKING TO THE FUTURE

Screening is set to change in many ways over the next decade and must evolve if it is to fulfil its potential to save yet more lives. Significant scientific developments are also now on the horizon which have the potential to change the nature of current screening approaches. The advent of more targeted screening techniques means that those at higher risk of a condition can be targeted. The genomic revolution similarly means that testing for multiple genes to create polygenic risk scores is becoming both feasible and more affordable. New technologies including artificial intelligence will support hard worked healthcare professionals in the delivery of screening by freeing up capacity.

Further detail on these developments and their potential is set out in Chapter 2. Urgent change is needed to ensure screening programmes can be readied and resourced to maximise the opportunities they bring.

APPROACH TAKEN FOR THIS REVIEW

This independent review was announced in November 2018, initially as a review of cancer screening programmes in England and in the context of two recent national incidents. The learning from investigations into these incidents collectively forms part of the context for this report, along with other concerns that have been raised about the functioning of screening programmes.

In parallel to publication of an interim report in May 2019, the scope of this review was significantly extended to include the AAA and DES screening programmes. The recommendations and findings of this review are based on

engagement with a wide range of stakeholders and key partner organisations including arms-length bodies, regulators, local government, local service providers, charities and patient representative groups. Further detail is provided in Chapter 3.

WHERE ARE WE NOW?

England can and should take pride in its NHS screening programmes. Backed by a strong evidence base, these programmes collectively invite over 15 million people for screening each year, of whom over 10 million take up the invitation. Overall, they are estimated to save around 10,000 lives each year.

Each screening programme is likely to undergo further improvement and change over coming years. The extension of the bowel screening programme has already been agreed in principle as a key element in the NHS Long Term Plan, whilst further changes are in the pipeline for cervical and breast screening, subject to evaluation findings. The latest figures show that collectively, the screening programmes currently cost over £660 million each year.

There is, however, a sense that we are now slipping. Whilst each programme is broadly achieving its intended goal of reducing mortality or blindness, each could undoubtedly also do better. The transitions described above are proving complex. Specific problems and challenges hinder their progress and performance, some of which are shared and some of which are unique.

Further information on each of these programmes is set out in Chapter 4 and accompanying appendices.

GOVERNANCE

Governance and accountability of screening programmes has evolved with the introduction of the 2012 Health and Social Care Act. Whilst this has undoubtedly had some benefits, implementation of the annual public health functions agreement (known as Section 7A services), has also blurred the lines of ownership and accountability.

The current tripartite governance arrangements create challenges along the screening pathway. Leadership and accountability are unclear to most observers and the division of responsibilities between Public Health England (PHE) and NHS England (NHSE)¹ creates confusion, delays and risks to patient safety. This is compounded by the plethora of national and sub-national governance committees and meetings which provide advice on screening programmes and contribute to oversight of their delivery.

New population screening programmes – or changes to existing programmes – require recommendations to be made to Ministers. A separation of functions between the UK National Screening Committee (UK NSC) for population screening, and the National Institute for Health and Care Excellence (NICE) on

¹ Public Health Commissioning, under the Section 7a agreement, is a statutory responsibility of NHS England having been delegated by the Secretary of State for Health and Social Care. In this context, this report refers to NHS England rather than NHS England and NHS Improvement.

targeted screening, is widely considered to be an unhelpful historical anomaly and means that targeted screening programmes do not receive the same guarantees of investment. Concerns have also been expressed that the horizon scanning function is not as forward looking or timely as it might be, leading to delays in implementation. A prime example is implementation of the Faecal Immunochemical Test (FIT) for bowel screening. An evaluation of the original pilot suggested in 2003 that immunochemical testing should be considered. However, it took until late 2015 for the UK NSC to make a recommendation in favour of implementation, which in turn did not commence until June 2019.

There is a pressing need to simplify governance and improve accountability, ownership and oversight. Further detail is set out in Chapter 5.

This review recommends that:

Recommendation 1: The Chief Medical Officers of the UK should bring together an advisory group to agree Terms of Reference for a new single screening advisory body. These terms of reference should be kept under regular review. This screening advisory body should cover both population and targeted screening, have an effective horizon scanning function, undertake and commission evidence reviews, and model impact and cost effectiveness.

Recommendation 2: Recommendations on targeted screening should be given the same weight and funding commitments as those for population screening and should be commissioned through the Section 7A agreement according to nationally agreed standards and service specifications.

Recommendation 3: NHSE and PHE should produce a roadmap for the transfer of relevant staff with expertise on screening delivery from PHE to NHSE to support their respective future roles. This roadmap should also consider how NHSE would integrate the delivery of targeted and population screening.

Recommendation 4: Following decisions by Ministers, NHSE should assume sole responsibility for the delivery of screening programmes, appointing a named director responsible for screening, so that it is clear to all stakeholders who is in charge. This should include both the implementation of Ministerial decisions on screening and 'business as usual' matters, including commissioning, performance management, monitoring and audit. NHSE should

work closely with PHE on the advice, NHSX on IT implementation and Health Education England (HEE) in relation to workforce.

Recommendation 5: The screening quality assurance service which is currently accountable to PHE should also transfer to NHSE but should be ring-fenced as part of the Section 7A mandate. Local quality assurance reports and a national overview report should be published annually. These reports should be shared with the Care Quality Commission (CQC) to inform assessments of screening service providers, with CQC taking enforcement action to address quality issues where required. This would align the quality assurance processes with those for the rest of NHSE commissioned services.

Recommendation 6: NHSE should publish an annual report on population and targeted screening performance. This should include progress on extension and improvements to existing programmes and implementation of new programmes, high level metrics and summary information on incidents and other quality parameters. More detailed reports should be published on each of the individual programmes.

Recommendation 7: At national level, NHSE should consider how to build on existing programme board arrangements to deliver its accountability for delivering both population and targeted screening programmes. Arrangements should incorporate expertise from PHE, NHSX, NHS Digital, HEE and NHSE regions and other directorates as required.

Recommendation 8: Local commissioning of both population and targeted screening should be aligned with the new regional structure of NHSE. Regional Directors should be accountable for the screening functions within their geographical areas and should ensure delivery against key performance indicators.

Recommendation 9: NHSE should consider how to improve and standardise local oversight of population and targeted screening, bringing together the current expertise from the quality assurance and commissioning teams. These teams will need to work closely with commissioners on relevant services for patients who present symptomatically (e.g. mammography, endoscopy, colposcopy and hospital eye services). Local commissioning teams should

be aligned as far as possible with Sustainability and Transformation Partnerships / Integrated Care Systems. This would be assisted by proposals for planned legislation to enable national and local commissioners to work together.

Recommendation 10: Local commissioners should work closely with cancer alliances, local authorities, and emerging primary care networks to ensure close join-up at local level, particularly where planned implementation of screening will impact on related service delivery. An example of this is the expected temporary increase in the number of colposcopies needed as a result of the move to primary HPV testing within the NHS cervical screening programme.

INFORMATION SYSTEMS

Information systems to support screening currently sit in an over-complicated landscape which hinders the delivery of screening programmes, leading to inefficiencies and errors. Some of the systems – particularly those for breast and cervical screening – are old and liable to fail. None have the full functionality required now or for the future.

It is very welcome that NHSX has adopted screening IT systems as one of their flagship programmes and that progress is already being made. It will be important to progress this work programme at pace and under close scrutiny.

This review recommends that:

Recommendation 11: NHSX should set out a roadmap for the delivery of new targeted and population screening IT systems as soon as possible, with a primary focus on the challenges with cervical and breast screening programmes and with regular reports on progress provided to the Department of Health and Social Care and NHSE.

Recommendation 12: This review recommends that the development of screening IT systems should include a necessary focus on the functionality needed to support improvements in the uptake and coverage of screening and take into account the specific needs of population and targeted screening approaches.

UPTAKE AND COVERAGE

Any screening programme can only achieve its goals if a significant proportion of the eligible population choose to participate. An international trend is emerging that, in both breast and cervical screening programmes, a decreasing proportion of women are being screened. This is a major concern and must be reversed.

Several local initiatives have been undertaken to improve uptake and coverage, with examples including social media campaigns to raise awareness and the issuing of text message reminders to those due to be screened. Many have had encouraging success which could be replicated more widely, subject to evaluation. Improving convenience, acceptability and accessibility – particularly for under-served groups in our society – are other key factors which should be considered. Further detail is set out in Chapter 7.

This review recommends that:

- Recommendation 13:** High priority should be given to spreading the implementation of evidence-based initiatives to increase uptake. This will require an integrated system approach and should include:
- Implementing text reminders for all screening programmes
 - Further pilots of social media campaigns with formal evaluation and rollout if successful
 - Spreading good practice on physical and learning disabilities
 - Encouraging links with faith leaders and community groups and relevant voluntary, community and social enterprise organisations that work with the NHS at national, regional and local levels to reduce health inequalities and advance equality of opportunity
 - Increasing awareness of trans and gender diverse issues amongst screening health professionals
 - Consideration of financial incentives for providers to promote out of hours and weekend appointments.

WIDER PERFORMANCE ISSUES

The vast majority of people who undergo screening will have normal findings. It is nonetheless important for them to receive results without delay, so that they can be reassured. Where abnormalities are found, it is an important part of

any screening programme that there are appropriate further investigations and treatment for those who require it, and that these are undertaken as soon as is reasonably possible.

Alongside uptake and coverage, other key performance indicators (KPIs) are vital in measuring the safety and quality of screening. Of the wide range of KPIs in place across screening programmes, this review has considered those which are particularly likely to affect patient outcomes and experience. It is worth noting that some of these were also highlighted in the earlier reports of the National Audit Office and Public Accounts Committee.

Breast cancer screening provides a good example of this. In 2017/18, 8% of women waited more than 36 months between breast screening appointments. If women are made to wait longer than 36 months between screens, the risk of cancers developing and presenting symptomatically increase. These cancers may be incurable.

Further detail is set out in Chapter 8.

This review recommends that:

Recommendation 14: Breast screening providers should aim to invite people at 34-month intervals after their previous appointment so that all participants can be screened within 36 months and therefore avoid slippage.

Recommendation 15: Across all screening programmes, getting the results of screening to patients within the standard timeframes should be achieved. This is particularly important for cervical screening where performance has fallen markedly.

Recommendation 16: Time to assessment and where necessary, further treatment, should be closely monitored across all programmes and publicly reported as part of faster diagnosis standards.

FINANCIAL INCENTIVES TO IMPROVE OUTCOMES AND UPTAKE OF SCREENING

Many screening programmes are currently provided through block contracts, which provide limited financial incentive to providers to actively improve uptake. Locally-led initiatives to improve uptake and coverage could be further enhanced and supported through the introduction of financial incentives for providers of services. This might include the introduction of payment by activity, targeted payments for enhanced services or enhancements to GP payment systems at either practice or primary care network level. This also has the potential to improve the quality of screening services.

Potential application is set out in Chapter 9.

This review recommends that:

Recommendation 17: NHSE should urgently consider how best to use financial incentives to increase uptake of cancer screening services and to encourage providers to prepare for the future, especially with regard to bowel screening.

CREATING CAPACITY FOR CHANGE

Screening programmes are currently constrained by the size and nature of their workforce, and the equipment and facilities available to them, which will act as a barrier to implementing the recommendations set out in this report unless immediately addressed. Creating capacity for this to change is key to ensure that screening programmes are fit for the future.

There are many pressures facing screening programmes which directly impact capacity. On bowel screening, more screening colonoscopies will be required, with overall endoscopy capacity needing close management over the next few years as a result. The expanding eligible population for breast screening – largely due to the maturing age of the baby boom generation – means extra demand for screening. With symptomatic breast services experiencing a similar increase in workload, both find themselves in competition for the same services and facilities. The replacement of capital equipment, including both mammography machines and mobile vans, also tends to be unaffordable for trusts given severe constraints on capital funding and huge demands for other capital investment, such as backlog maintenance. The Prime Minister's recent announcement of new funding to replace old screening and diagnostic equipment is a welcome first step. Further detail is set out in Chapter 10.

This review recommends that:

Recommendation 18: National guidance should be provided to allow local commissioners and providers to plan for the required changes in colonoscopy and any future screening programme changes. Commissioners of screening and symptomatic services will need to work together on this. Cancer Alliances can facilitate this working in collaboration with the NHSE public health commissioning teams.

Recommendation 19: Training of screening colonoscopists should be given very high priority by HEE. Providing endoscopists who are already undertaking symptomatic colonoscopies with additional skills should be encouraged.

Recommendation 20: A dedicated capital fund or similar approach to support the purchasing of screening equipment and facilities should be established to replace old

equipment and meet future activity increases, given the competing priorities for capital allocation in the system.

IMPROVING AUDIT AND RESEARCH

The NHS in England provides a valuable platform for research that is second to none. Efforts should be made to utilise this opportunity to support research into possible new screening programmes.

It is also clearly important that existing screening programmes continue to be subject to routine audit and evaluation to understand whether each one is fulfilling its potential. The UK has a cadre of top-quality academic researchers and has funding agencies prepared to support research in this area. However, serious obstacles – especially in access to data – hinder progress and cause major frustration.

Data availability is particularly lacking in some programmes, with comparability, completeness and timeliness of publication being key issues. Whilst recognising the need to protect personal data and ensure the smooth running of programmes, this research is vital to understanding improvements that can save more lives. Further detail is set out in Chapter 11.

This review recommends that:

Recommendation 21: Routine audit data on each of the five adult programmes should be published by NHSE, at least annually, so that the public can be assured that the services are operating as expected. This should include appropriate equality data to support monitoring of uptake in under-served groups.

Recommendation 22: The process for releasing data for research purposes should be reviewed and simplified, with timelines being set for decisions by individual committees, including the Office for Data Release. Further approval processes should be consolidated across different organisations with carefully defined remits documented for all parties, including data sharing arrangements.

1. WHAT DO WE MEAN BY SCREENING?

Screening is a widely used term in the NHS. This chapter sets out the different forms of screening that people may encounter as part of NHS care. It also clarifies which of these falls within the scope of this review.

INTRODUCTION

The term 'screening' is widely used throughout the health care setting. It can take various forms, ranging from national population screening programmes (e.g. breast screening) through to screening that occurs as part of routine care (e.g. a GP screening for high blood pressure). For the purposes of this review, we have considered a hierarchy of screening as follows:

- National population screening programmes which target large groups of the population to screen for early signs of cancer or disease (e.g. cervical cancer screening for all women aged between 25 and 64)
- Targeted or risk stratified screening which seeks to target screening at people who are at higher risk of a cancer or disease (e.g. targeted screening for women who have a family history of breast cancer)
- NHS Health Checks for all people aged between 40 and 74
- Lung Health Checks, currently being piloted for current and ex-smokers
- Opportunistic screening, recommended for certain groups of people but which doesn't involve them being actively invited for screening (e.g. screening young sexually active people for chlamydia)
- Screening delivered as part of routine health care.

Further detail on each type of screening is set out below.

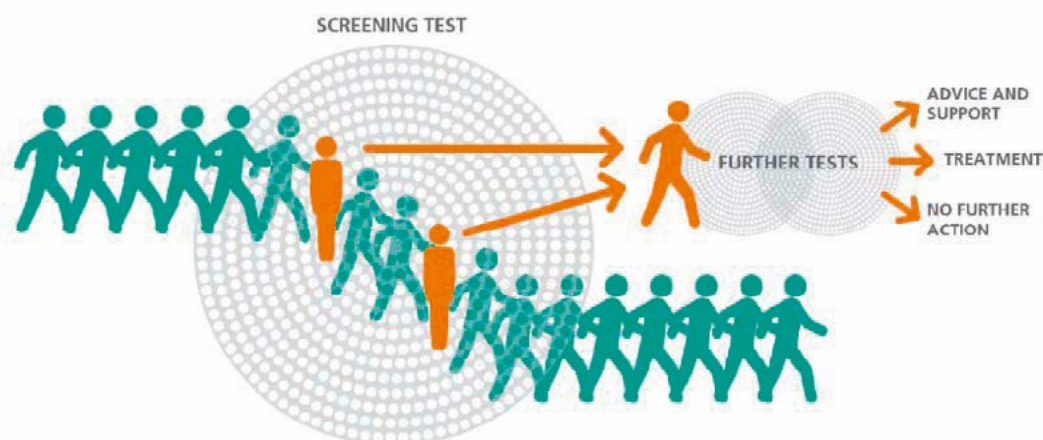
NATIONAL POPULATION SCREENING PROGRAMMES

The UK National Screening Committee (UK NSC) defines screening as “the process of identifying healthy people who may have an increased chance of a disease or condition. The screening provider then offers information, further tests and treatment. This is to reduce associated problems or complications. Screening should always be a personal choice.”²

National population screening programmes in England are recommended by the UK NSC and funded by NHS England via a ring-fenced (Section 7A) budget agreed by the Department of Health and Social Care. They target large

² UK National Screening Committee. 2018. Screening in the UK: making effective recommendations. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733226/Screening_in_the_UK_making_effective_recommendations_2017_to_2018.pdf [Accessed 18 September 2019].

population groups to assess for early signs of cancer or disease. Their aim is to lower incidence and improve early diagnosis and outcomes for patients. Over 10 million adults attend screening appointments each year³.



Source: Gov.uk⁴

The large majority of people who attend population screening will be found to have no abnormality. People who are picked up by screening as having an abnormal test result will require further tests or investigations to diagnose or rule out the disease or condition.

No screening test is 100% effective. It is important to recognise that some people will be screened who have the condition and it will not be detected. Similarly, others may receive a ‘false positive result’ and find themselves subjected to further tests or possibly more invasive procedures that are entirely unnecessary and cut across the principle to ‘first do no harm’. Screening programmes are effectively judged on whether the benefits to those who get earlier treatment outweigh the harms to those people who get treated unnecessarily, or who are subject to unnecessary anxiety.

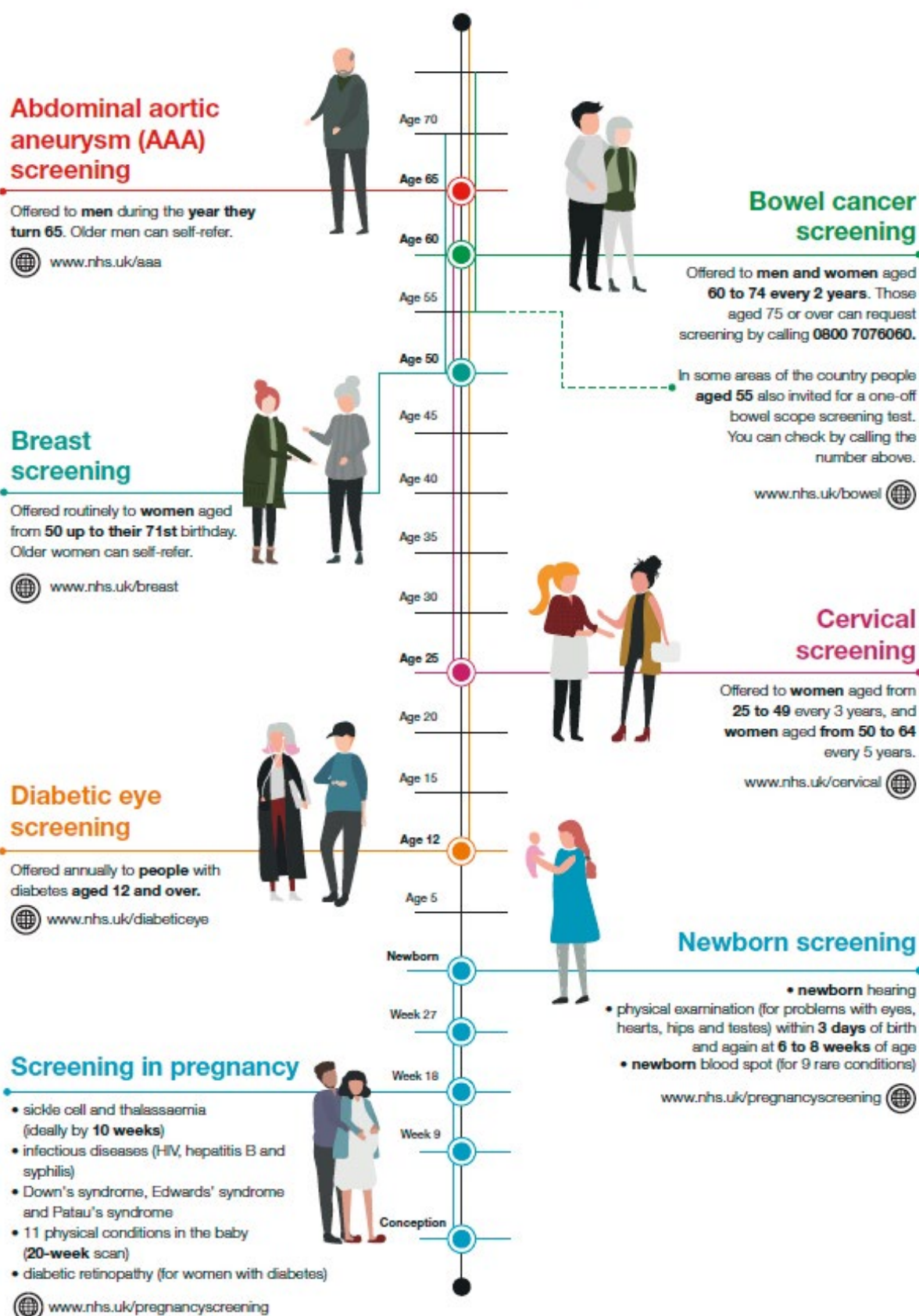
The following timeline – originally developed by the Shrewsbury and Telford Hospital Trust – outlines the various population screening programmes that are currently available from antenatal screening through to adult screening. The process to determine whether a condition or disease should be considered a population screening programme follows a specific set of criteria. This concept was initially introduced in 1968 by Wilson and Jungner⁵ who set out ten screening criteria in a paper commissioned by the World Health Organisation. The UK NSC last updated their national screening criteria in 2015. These criteria and a full list of current population screening programmes in England are set out in **Appendix B**.

3 Public Health England. 2018. NHS Screening Programmes in England. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/783537/NHS_Screening_Programmes_in_England_2017_to_2018_final.pdf. p8.

4 Gov.uk. 2019. Illustration of the screening process. [ONLINE] Available at: <https://www.gov.uk/guidance/nhs-population-screening-explained#illustration-of-the-screening-process>.

5 Wilson JMG, Jungner G. Principles and practices of screening for disease. Geneva, Switzerland: World Health Organization; 1968.

Population screening timeline



Source: Gov.uk⁶

6 Public Health England. 2019. Population Screening Timeline. [ONLINE] Available at: <https://phescreening.blog.gov.uk/2019/07/23/brilliant-new-screening-timeline/>

Five of these programmes (for abdominal aortic aneurysm, bowel cancer, breast cancer, cervical cancer, and diabetic eye) are distinguishable by the fact that they require people to be actively invited for screening and recalled as appropriate, and they involve young people and adults. It is these specific programmes that form the focus of this review.

TARGETED OR RISK STRATIFIED SCREENING

Targeted or risk stratified screening programmes are aimed at specific groups of people who have a higher than average risk of developing the disease or condition they are being screened for. Currently, this is based largely on genetic information or having a strong family history of a disease. In future, it may be based on other factors including smoking history, vaccination history, genomic profile (polygenic risk scores), breast density and new biomarkers.

Targeted programmes are currently recommended by the National Institute for Health and Clinical Excellence (NICE) within some clinical care guidelines. In general, they are variably funded by clinical commissioning groups. An example of this is targeted screening for women with a family history of breast cancer, who are at moderately elevated risk of developing the cancer themselves. To be effective, these programmes rely on the accurate recording and availability of data on risk factors so that eligible patients can be offered screening at appropriate ages and intervals. Targeted programmes also require a mechanism by which to deliver set standards, write specifications, train staff, monitor the process and outcomes, and undertake quality assurance. Further information is set out in Chapter 2.

The boundary between population and targeted screening is somewhat arbitrary. Diabetic eye screening, for example, could be considered a targeted screening programme as it only invites people with diabetes, however it is considered a national population screening programme by the UK NSC as all people with diabetes registered with a GP can be identified and invited for screening.

NHS HEALTH CHECKS

NHS Health Checks are a form of population screening but have not been recommended by the UK NSC. They are largely delivered by primary care services, based on guidance issued by Public Health England⁷. In general, funding is sourced via local authorities through their public health spend allocation. All patients aged 40-74 are offered a health check which aims to prevent cardiovascular disease, and associated conditions, through the early assessment, awareness and management of individual and physiological risk factors. In 2018/19, around 2.7 million people were invited of whom 1.3 million (45.9%) received an NHS Health Check⁸.

7 NHS Health Check. 2019. National Guidance. [ONLINE] Available at: <https://www.healthcheck.nhs.uk/commissioners-and-providers/national-guidance/>

8 NHS Health Check. 2019. NHS Health Check - Data. [ONLINE] Available at: <http://www.healthcheck.nhs.uk/commissioners-and-providers/data/>. [Accessed 17 September 2019].

The NHS Health Check programme is estimated to prevent 1,600 heart attacks and strokes, prevent 4,000 diabetes cases, detect 20,000 cases of diabetes or kidney disease and avoid at least 650 premature deaths each year⁹.

In July 2019, the DHSC issued a consultation on proposals to tackle the causes of preventable ill health in England¹⁰, which includes plans to review the NHS Health Check and explore how to improve the system, with a focus on offering personalised interventions based on factors such as age, where people live and genomic information. The consultation runs until October 2019.

LUNG HEALTH CHECKS

These are currently being piloted by NHS England as part of the NHS Long Term Plan¹¹, taking into account promising findings from two international randomised trials^{12,13} and some early pilot schemes in deprived areas of England. The Lung Health Check pilots invite people identified from GP records as current or ex-smokers and will be rolled out across ten cancer alliances over the next two years¹⁴. Participants taking up their invitation will be assessed for their risk of lung cancer and, for those at increased risk, will be offered a low dose CT scan if eligible. Spirometry and other add-on health interventions may also be offered.

If the pilots succeed, it is intended that the programme will be rolled out nationally, and also that those in the programme will continue to be screened up to the age of 75 for their first CT scan, and 77 for their final CT scan. These are effectively pilots for a national screening programme and are discussed in more detail in Chapter 2.

OPPORTUNISTIC SCREENING

Opportunistic screening refers to tests that are recommended for certain groups but don't involve actively inviting people for a test. Chlamydia screening is an example of opportunistic screening where the recommendation is that young, sexually active people are regularly tested for chlamydia.

The National Chlamydia Screening Programme was established in 2003 and aims to ensure all sexually active people who are under 25 years old are informed about chlamydia and have access to sexual health services that can reduce the risk of infection or transmission. It has the following objectives¹⁵:

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- 9 NHS England. 2014. Factsheet: Implementation of the NHS Health Check programme. [ONLINE] Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/02/pm-fs-3-1.pdf>
 - 10 Gov.uk. 2019. Advancing our health: prevention in the 2020s. [ONLINE] Available at: <https://www.gov.uk/government/consultations/advancing-our-health-prevention-in-the-2020s>
 - 11 NHS England. 2019. The NHS Long Term Plan. [ONLINE] Available at: <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
 - 12 NELSON Dutch Belgian randomised lung cancer screening trial ISRCTN. 2006. ISRCTN. [ONLINE] Available at: <http://www.isrctn.com/ISRCTN63545820>. [Accessed 17 September 2019].
 - 13 The New England Journal of Medicine. 2011. Reduced Lung-Cancer Mortality with Low-Dose Computed Tomographic Screening. [ONLINE] Available at: <https://www.nejm.org/doi/full/10.1056/NEJMoa1102873>. [Accessed 17 September 2019].
 - 14 NHS England - News. 2019. NHS to rollout lung cancer scanning trucks across the country. [ONLINE] Available at: <https://www.england.nhs.uk/2019/02/lung-trucks/>. [Accessed 17 September 2019].
 - 15 Gov.uk. 2003. National Chlamydia Screening Programme (NCSP). [ONLINE] Available at: <https://www.gov.uk/government/collections/national-chlamydia-screening-programme-ncsp>. [Accessed 17 September 2019].

- To prevent and control chlamydia through early detection and treatment of infection
- To reduce onward transmission to sexual partners
- To prevent the consequences of untreated infection
- To normalise the idea of regular chlamydia screening among young adults so they expect to be screened annually or when they change partner.

As part of the programme, chlamydia screening is embedded within many services in primary and secondary care, and other local authority funded services. This includes sexual and reproductive health clinics, general practice, abortion services, community pharmacies and internet-based testing where kits are sent to the young person's home address. In 2018, 1.3 million chlamydia screening tests were carried out on 15-24 year olds, resulting in over 130,000 chlamydia diagnoses¹⁶.

SCREENING DELIVERED AS PART OF ROUTINE HEALTH CARE

Other types of screening also occur during the provision of healthcare which are not part of a national screening programme. Examples of this include:

- A dentist screening for oral cancer during a routine check-up
- An optometrist screening for glaucoma during an eye examination
- A nurse screening for MRSA in a hospital setting
- A midwife screening for gestational diabetes
- A GP screening for high blood pressure during an appointment for another problem.

SUMMARY

Screening is a widely used term in the NHS and can take various forms. The primary focus of this review is on national population screening programmes and targeted screening programmes offered to young people and adults only. These programmes also require people to be actively called and recalled for screening.

As a pre-requisite, the review has had an important focus on looking to the future. Further developments to screening are now on the horizon which, if taken up by the NHS, will lead to even more lives being saved. This is considered in more detail in the following chapter.

¹⁶ Sexually transmitted infections and screening for chlamydia in England, 2018. Public Health England. Health Protection Report Volume 13 Number 19 [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/806119/hpr1919_stis-ncsp_ann18.pdf?_ga=2.235908353.1648254530.1566896068-1096460402.1555324401. [Access 17/09/2019].

2. LOOKING TO THE FUTURE

This chapter considers the future direction of screening. More effective horizon scanning and planning for changes are essential if we are to deliver programmes in a way that is as efficient as possible to maximise on lives saved.

INTRODUCTION

Screening is set to change in many ways in the near and not-so-near future. The Department of Health and Social Care recently set out a vision for future screening in the NHS¹⁷ which calls for screening that is easier to access; that is more personalised and stratified by risk so that interventions are focused where they are most needed; that makes better use of technology and that sees developments being implemented more quickly, with clear accountability for delivery.

Many barriers and issues will first need to be addressed if NHS screening programmes are to realise this vision. First, it is useful to understand how screening is expected to change:

- Possible new population screening programmes
- Expansion of targeted screening approaches
- New biomarkers
- The genomic revolution: Polygenic risk scores
- Artificial intelligence

Each of the five adult population screening programmes considered as part of this review are also likely to undergo further specific improvements over the coming years. These are set out in Chapter 4.

POSSIBLE NEW POPULATION SCREENING PROGRAMMES

Before a new population screening programme can be introduced, rigorous assessments of the balance between benefits, harms and cost effectiveness are rightly required. These usually require randomised controlled trials.

As an example, the UK National Screening Committee currently recommends against prostate cancer screening using the Prostate Specific Antigen (PSA). The evidence from randomised trials on the reduction of mortality is inconsistent. There is also widespread agreement that the risk of overdiagnosis and overtreatment, which can potentially lead to incontinence and impotence,

17 Gov.uk. 2019. Advancing our health: prevention in the 2020s.

currently outweighs the benefits at a population level. Further trials using PSA and other biomarkers in association with modern MRI techniques are now awaited^{18,19}.

A large-scale trial to assess screening for ovarian cancer using a biomarker (CA 125) and/or ultrasound has also been undertaken. Longer follow up is needed to assess whether this leads to a significant reduction in mortality²⁰. A trial is also underway to assess a new approach to identifying people at risk of developing oesophageal cancer, which also carries a poor prognosis when patients present with symptoms.

Case Study: Cytosponge™ research (BEST3 Trial)

Cytosponge is a minimally invasive cell sampling device which can be used to help identify people with Barrett's oesophagus, the main risk factor for oesophageal adenocarcinoma. The Cytosponge is contained within a small capsule which is attached to a string and, when swallowed, dissolves after 3-5 minutes. When the sponge is retrieved by pulling on the string, it collects samples from cells lining the oesophagus which are stained for the biomarker Trefoil Factor 3 (TFF) to identify people who should be referred for endoscopy.

BEST3 is an ongoing trial to investigate the use of Cytosponge-TFF3 in primary care for people with certain symptoms that might lead to development of Barrett's oesophagus. Cytosponge is an innovative test that, depending on the results from BEST3, could be used to screen individuals at high-risk of oesophageal cancer²¹.

EXPANSION OF TARGETED SCREENING APPROACHES

A large number of people interviewed for this review and almost half of those who responded to the call for evidence strongly supported more extensive use of targeted screening for groups with a higher than average risk of developing a particular form of cancer or other disease. New targeted screening programmes may include screening for cancers and other types of disease, and may be based on:

- **Screening of families of people with genetic abnormalities** Lynch syndrome, which increases the risk colorectal cancer, is a good example of this.

18 The Lancet. 2017. Articles|Volume 389, ISSUE 10071, P815-822, February 25, 2017 Diagnostic accuracy of multi-parametric MRI and TRUS biopsy in prostate cancer (PROMIS): a paired validating confirmatory study. [ONLINE] Available at: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)32401-1/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)32401-1/fulltext). [Accessed 17 September 2019].

19 UCL Division of Surgery and Interventional Science. 2019. REIMAGINE Trial Information. [ONLINE] Available at: <https://www.ucl.ac.uk/surgery/research/situ-trials/reimagine/reimagine-trial-information>. [Accessed 17 September 2019].

20 Ovarian cancer screening and mortality in the UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS): a randomised controlled trial. 2016. Lancet. 2016 Mar 5; 387(10022): 945-956.. [ONLINE] Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779792/>. [Accessed 17 September 2019].

21 US National Library of Medicine National Institutes of Health. 2018. BMC Cancer. 2018; 18: 784. Barrett's oESophagus trial 3 (BEST3): study protocol for a randomised controlled trial comparing the Cytosponge-TFF3 test with usual care to facilitate the diagnosis of oesophageal pre-cancer in primary care patients with chronic acid reflux. [ONLINE] Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6091067/>. [Accessed 17 September 2019].

- **Lifestyle/behavioural factors** Targeting screening at smokers and ex-smokers is being tested through the Lung Health Check programme (see Chapter 1).
- **Imaging findings** Women with dense breasts have a higher risk of developing breast cancer than others. Cancers may also be more difficult to diagnose in these women, so targeted programmes may be appropriate.

Case study: Screening for Lynch syndrome (colorectal cancer)²²

Lynch syndrome is an inherited condition resulting from genetic mutations affecting DNA mismatch repair. It is estimated that around 3.3% of colorectal cancers are due to Lynch syndrome (i.e. around 1,000 cases per annum in England). It is also estimated that around 170,000 people in the UK are living with Lynch syndrome, many of whom are unaware of it.

In 2017, the National Institute for Health and Care Excellence (NICE) recommended that all people with colorectal cancer should be offered testing when first diagnosed, and provided guidance on a series of sequential tests. This indicated that a strategy of testing those diagnosed with colorectal cancer (irrespective of age), combined with testing an average of six family members (first or second degree), would be cost effective.

At the time the guidance was published however, it was estimated that only half of all available centres were offering testing for Lynch syndrome, and most of these restricted testing to patients aged less than 50 years. In 2018, Bowel Cancer UK submitted a Freedom of Information (FOI) request asking Clinical Commissioning Groups (CCGs) in England if they are funding hospitals to carry out Lynch syndrome testing. The FOI found that only 13 (6%) out of 204 CCGs commissioned their local hospital(s) to test all bowel cancer patients in line with NICE guidance, 65% of CCGs stated they do not commission Lynch syndrome testing in newly diagnosed bowel cancer patients, with the remaining 29% stating they did not know what services were provided at local hospitals or do not hold the level of information²³. Recent unpublished evidence presented to this review from molecular testing laboratories additionally suggests that fewer than 20% of people with colorectal cancer are tested. Based on this information, screening of family members at high risk of colorectal cancer is currently inadequate.

22 NICE Guidance. 2017. Molecular testing strategies for Lynch syndrome in people with colorectal cancer. [ONLINE] Available at: <https://www.nice.org.uk/guidance/dg27/chapter/2-Clinical-need-and-practice#the-condition>. [Accessed 17 September 2019].

23 Beating Bowel Cancer and Bowel Cancer UK. 2019. Time to Test. [ONLINE] Available at: <https://bowelcancerorguk.s3.amazonaws.com/Campaigns/LYNCH%20SYNDROME%20REPORT%20FINAL.pdf>

Case study: Targeted screening for breast cancer

Family history and inherited genetic mutations increase an individual's risk of developing breast cancer. NICE provide guidance on care for people at an increased risk of familial breast cancer, which may include referral to a specialist genetic clinic²⁴. Women found to be at elevated risk should be offered appropriate screening.

Women known to be at high risk of breast cancer (defined as having $\geq 30\%$ lifetime risk) are currently screened through the national screening programme, though this is not part of a formal UK NSC recommendation. This group includes those known to have mutations in certain genes (*BRCA1*, *BRCA2* or *TP53*). Women in this group also have a $\geq 8\%$ risk of developing breast cancer between the ages of 40 and 50 years, so screening starts earlier than for the national screening programme. They are also screened more frequently through a combination of mammography and MRI.

Women are defined as being at moderately elevated risk of breast cancer if they have a $\geq 17\%$ but $\leq 30\%$ lifetime risk. This group also have a 3-8% risk of developing breast cancer between 40 and 50 years. Many women with a strong family history of breast cancer will fall into this group. However, at present screening for this group of women is not managed through the national screening programme and is funded through local, rather than national, commissioning arrangements. Respondents to this review repeatedly commented that screening for this group is variable and suboptimal across the country.

If high risk groups can be accurately identified, the benefits are more likely to outweigh the harms posed by the risk of false positive or negative results as described in Chapter 1. By restricting screening to a smaller number of patients, affordability and cost effectiveness could also improve. However, the UK NSC does not normally consider programmes unless they would apply to a whole segment of the population.

24 NICE Guidance. 2013. Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer. [ONLINE] Available at: <https://www.nice.org.uk/guidance/cg164/ifp/chapter/Early-detection-of-breast-cancer-by-surveillance>. [Accessed 17 September 2019].

NEW BIOMARKERS

Much research is underway to identify whether specific biomarkers may be helpful for screening. A good example is 'circulating DNA'. Cancers may shed DNA into the bloodstream before they cause symptoms. The potential for blood tests which detect such circulating DNA to screen for a range of cancers is currently being evaluated.

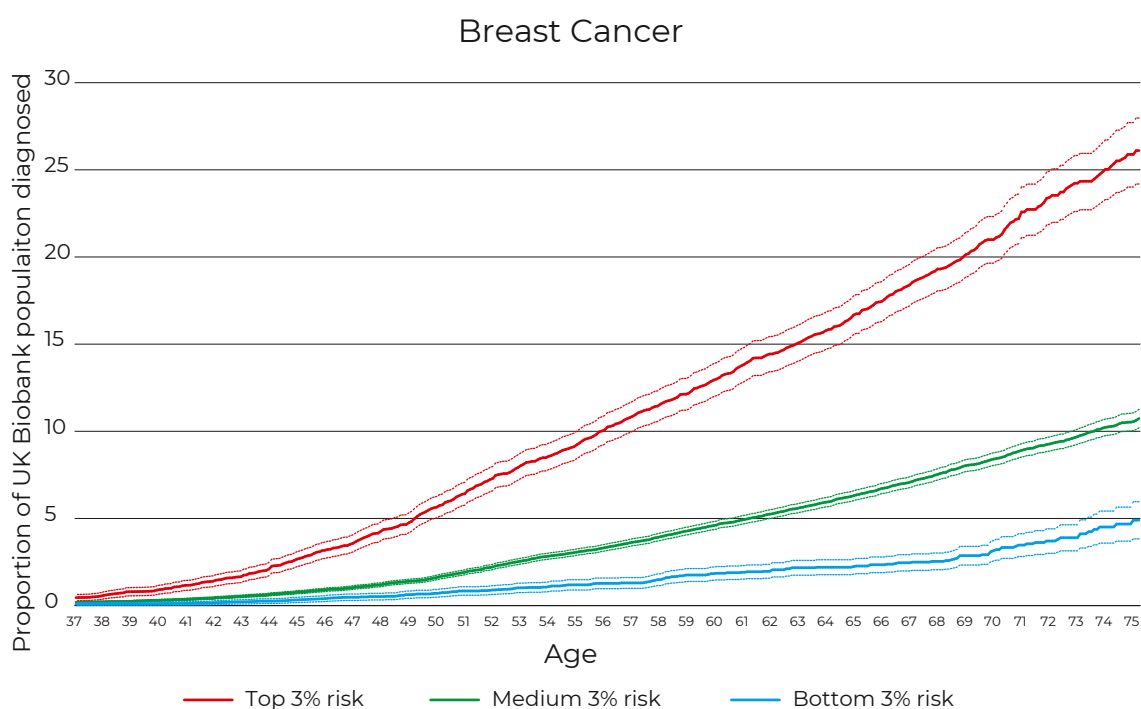
Case Study: The SUMMIT Study (GRAIL Inc.)

The SUMMIT Study is a clinical trial partnership between University College London (UCL), UCL Hospitals and GRAIL Inc., an American Healthcare company. The study primarily aims to add to the evidence base around feasibility and implementation of a lung cancer screening programme in the UK. However, a secondary aim is to develop a multi-cancer blood test analysing levels of circulating tumour DNA to detect cancers early in asymptomatic individuals. Samples will be collected from 50,000 participants of both higher and lower risk of lung cancer. Researchers propose that a blood test could be used to detect cancers for which no screening methods exist or to augment existing screening programmes. However, a major interventional study would be required before adoption of the blood test, potentially adding another five years to development timescales as well as requiring major investment.

THE GENOMIC REVOLUTION: POLYGENIC RISK SCORES

As referred to above, targeted screening is already offered to a limited number of individuals who have been shown to have mutations of individual genes which carry a very high risk of cancer (such as *BRCA1* and *BRCA2* for breast cancer). Recent research has shown that a large number of other genes may individually carry a small (1 or 2%) additional risk of a particular cancer. Collectively however, these genes may be associated with a much larger increase in risk. The presence of alterations in these genes can be combined into a 'polygenic risk score' or PRS. This means it is now possible to ascertain whether an individual is at high (or indeed low) risk of a wide range of conditions, including cancers and heart disease.

In the example given below, the blue line represents the breast cancer risk for all women, whilst the red line represents the risk of developing breast cancer with increasing age for those in the top 3% based on their PRS. The green line represents those in the lowest 3% based on their PRS.



Graph kindly supplied by Professor Sir Peter Donnelly, Genomics plc.

This will raise issues for screening programmes which require careful consideration. In the given example, a case can be made for offering screening from an earlier age for those in the highest risk group. The impact of screening such patients will need to be carefully evaluated. Research funding should be committed for this.

Although only a very small proportion of the population have as yet had their genome tested to create a PRS, this is set to change. The genomic revolution means that testing for multiple genes to create such PRS is becoming both feasible and more affordable. The government has recently committed £79m to an Accelerated Diagnosis of Disease research programme, which will evaluate the use of PRS and other tests to identify people at high risk of serious illnesses and new approaches to early detection of disease²⁵.

ARTIFICIAL INTELLIGENCE

Artificial Intelligence (AI) is likely to bring multiple benefits to healthcare over the coming years. AI algorithms are already at an advanced stage of development for interpreting mammograms and retinal images, for example.

25 Government News. 2019. Accelerated Diagnosis of Disease. [ONLINE] Available at: <https://www.gov.uk/government/news/13-billion-industry-government-investment-in-uk-economy-and-new-partnership-driving-early-disease-detection> [Accessed 17 September 2019]

Screening mammograms are currently read and reported independently by two highly trained radiologists or radiographers. Given current workforce challenges in breast screening, the advent of AI could prove hugely beneficial (see Chapter 10). Within very few years, it is envisaged that AI will have been sufficiently well tested to replace one of the two human readers. It is important to stress that this will not replace the need for radiographers and radiologists who undertake many other roles that are essential for the effective delivery of the programme. An example relating to AI for breast screening is set out below.

Case Study: Kheiron / East Midlands Radiology Consortium

The East Midlands Radiology Consortium (EMRAD), was launched in 2013 to create a common digital radiology system. Pioneering work led to the development of a cloud-based image-sharing system through which the seven NHS trusts involved in the partnership could share diagnostic images, such as x-rays and scans.

In 2018, EMRAD formed a partnership with two UK-based AI companies, Faculty and Kheiron Medical, to help develop and test AI tools in the breast cancer screening programme in the East Midlands. The project is one of seven 'wave two' NHS Test Beds and aims to develop and test both clinical and non-clinical (operational) AI tools. Realising the opportunities presented by AI will depend on the availability (and accessibility) of data to train such tools.

As part of their role in the Test Bed, Kheiron are conducting a large-scale retrospective study on mammograms from two NHS sites within the EMRAD. The aim is to test whether their deep learning mammography software, 'Mia', can be considered as an independent second reader in double-read screening programmes. This has the potential to support the screening workforce.

The Test Bed project is also assessing whether AI tools can help run operational and administrative aspects of the breast screening programme. Faculty's 'Platform' software is being evaluated to see where it can optimise operational processes such as clinic scheduling and staff resourcing. For example, AI tools could be used to accurately predict whether people will or won't attend their screening appointment, thereby allowing over-booking of clinics without impacting service quality.

AI developments will be further enhanced and accelerated by the recent announcement by the Secretary of State for Health and Social Care that £250 million will be invested in boosting the role of AI in the NHS, linking to industry investment in new state-of-the-art facilities in AI research²⁶. This should prove instrumental in taking this work forward. Whilst no panacea – and subject only to proper evaluation – AI has huge potential to enhance screening programmes and release workforce capacity, at the very least making workloads more manageable. The UK NSC has also recently set out its approach to assessing new AI offers and evaluating these programmes²⁷

THE NEED FOR CHANGE

Screening is set to change in many ways over the next decade. New population screening programmes may prove to be effective and cost effective, especially if new biomarkers are demonstrated to be useful for triage before more invasive tests are undertaken. Targeted screening will assume greater importance with polygenic risk scores and other tests identifying groups at high risks of individual conditions. New technologies including AI will support hard worked healthcare professionals in the delivery of screening. All can save yet more lives but rely on the programmes being readied and resourced if they are to be able to realise this potential.

26 Government News, 2019. Artificial Intelligence. [ONLINE] Available at: <https://www.gov.uk/government/news/health-secretary-announces-250-million-investment-in-artificial-intelligence>.

27 Gov.uk. 2019. New guidance for AI in screening. [ONLINE] Available at: <https://phescreening.blog.gov.uk/2019/03/14/new-guidance-for-ai-in-screening/>

3. APPROACH TAKEN FOR THIS REVIEW

This chapter sets out the background context which led to this review being announced, the terms of reference it has operated to and the approach it has taken to determine its recommendations.

CONTEXT

This independent review was announced by NHS England in November 2018, initially as a review of cancer screening programmes in England.

During the course of 2018, two high profile incidents, one in the breast screening programme and one in the cervical screening programme, gave rise to concerns about certain aspects of the running of the programmes. Both were subject to separate detailed investigations. The breast screening incident was investigated by an independent review team chaired by Lynda Thomas, CEO Macmillan Cancer Support, and the late Professor Martin Gore, with Peter Wyman as vice-chair. The National Audit Office subsequently conducted an investigation looking at several aspects of cancer screening, which reported in January 2019 and was the subject of a hearing by the Public Accounts Committee in March 2019.

The learning from these investigations collectively forms part of the context for this report, along with other concerns that have been raised about the functioning of screening programmes. In recognition of the fact that the recommendations of this review will have wider implications, its scope was extended in May 2019 to include other adult screening programmes in England.

TERMS OF REFERENCE

This final report is presented in line with terms of reference as agreed by the Secretary of State for Health and Social Care and the Chief Executive of NHS England and NHS Improvement, supported by Public Health England (PHE). These were initially set in November 2018, and later extended in recognition of the fact that the work of the review will have implications for the organisation of other adult screening programmes. Key aims of the extended review have been to assess:

- strengths and weaknesses in the current commissioning and delivery arrangements for the adult screening programmes in England, in view of the current available evidence.
- diagnostic capacity for screening (screen detected and symptomatic) taking account of the Faster Diagnosis Standard and likely future models of care.

The review will also make recommendations based on the findings from the above and on other areas including:

- the allocation of responsibilities between NHS England, PHE and the Department of Health and Social Care (DHSC) to translate screening policy into implementation;
- how future screening programmes should be commissioned, delivered, performance managed and quality assured;
- how to ensure that the necessary workforce is both available and appropriately trained to deliver the programmes;
- procurement of screening technologies (e.g. FIT);
- how IT systems support the ambitions of the screening programmes;
- opportunities for the use of artificial intelligence and stratification in screening, likely timescales and implementation approach;
- how best to maximise uptake of screening, and iron out variation in uptake rates between different geographical areas and different population groups;
- how best to integrate research and evaluation within screening;
- how best to ensure that screening supports the wider efforts being led by the NHS Cancer Programme to promote early diagnosis of cancer; and
- approaches to increasing diagnostic capacity both for screening and more widely.

A full copy of the Terms of Reference can be accessed on the NHS England website at: www.england.nhs.uk/publication/terms-of-reference-review-national-cancer-screening-programmes-england/.

SCOPE

A number of national population screening programmes are offered in England as approved by the UK National Screening Committee (UK NSC). In line with its extended terms of reference, this review largely focuses on a specific cohort of population screening programmes as set out in the previous chapter:

Screening Programme	Type
NHS Abdominal Aortic Aneurysm programme	Adult
NHS Bowel Cancer Screening Programme	Adult
NHS Breast Screening Programme	Adult
NHS Cervical Screening Programme	Adult
NHS Diabetic Eye Screening Programme	Young people (from age 12) and adults

Note that whilst this review considers some aspects of diagnostic capacity that are directly related to screening, its scope does not extend to diagnostic capacity more generally. This will be covered in a separate report due to be published later in 2019.

Newborn and antenatal screening programmes have not been considered as part of this review.

APPROACH TAKEN FOR THIS REVIEW

The recommendations and findings of this review are based on engagement with a wide range of stakeholders and key partner organisations including arms-length bodies, regulators, local government, local service providers, charities and patient representative groups. Since being established, the review has:

- reviewed recent reports on screening in England
- reviewed service specifications and reports published by PHE
- undertaken a limited literature review on interventions which increase uptake of screening, supported by discussions with key experts in the field
- held meetings with over 100 senior personnel
- held ten round tables involving over 300 personnel
- attended and spoken at relevant existing meetings including the UK NSC and governance meetings involving DHSC, PHE and NHS England and other advisory committees related to individual screening programmes
- run an open call for evidence
- held a focus group with people affected by cancer
- held a focus group at an adult learning centre in a highly diverse inner London borough (Haringey) with people of varying literacy levels, often with English as a second language
- initiated work on diagnostic capacity

The focus of discussion in each instance has been:

- what is working well and should be preserved
- what is working less well
- what modifications or improvements participants would like to see implemented

Further information on the activity of the review, including a full list of stakeholders consulted and a summary of the response to the open call for evidence, is set out in **Appendix A**.

TIMELINE

Despite progress made, screening programmes in England have experienced some well documented challenges...

- May 2018** Secretary of State for Health and Social Care announces a major failure in breast screening²⁸.
- November 2018** Secretary of State informs Parliament of another serious incident in cervical screening²⁹. NHS England announces an independent review of the national cancer screening programmes.
- December 2018** Findings of the Independent Breast Screening Review by Lynda Thomas and Professor Martin Gore are published³⁰.
- January 2019** The NHS Long Term Plan states findings of the current review will be taken forward as part of its implementation³¹.
- February 2019** The National Audit Office publish their investigation into the management of health screening (including an additional focus on abdominal aortic aneurysm)³².
- Mar 2019** The Public Accounts Committee hold a hearing on adult screening³³. NHS England announce that the management of the cervical screening 'call and recall' service is to be brought back in-house.
- May 2019** Interim findings of this review are published³⁴. Scope is extended to include all adult screening programmes in England.
- July 2019** Government set out response to PAC report³⁵.

28 UK Parliament. 2018. House of Commons Hansard - Breast Cancer Screening. HC Deb 02 May 2018 vol 640 col 315. [ONLINE] Available at: <https://hansard.parliament.uk/commons/2018-05-02/debates/BE9DB48A-C9FF-401B-AC54-FF53BC5BD83E/breastcancerscreening>. [Accessed 17 September 2019].

29 UK Parliament. 2018. National Cervical Screening Programme Incident: Written statement - HCWS1086. [ONLINE] Available at: <https://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2018-11-15/HCWS1086/>. [Accessed 17 September 2019].

30 Thomas, L. Gore, M, Wyman, P. The Independent Breast Screening Review 2018. 2018. Breast Screening Review 2018. [ONLINE] Available at: <http://breastscreeningreview2018.independent.gov.uk/>.

31 NHS England. 2019. The NHS Long Term Plan.

32 National Audit Office. 2019. Investigation into the management of health screening. [ONLINE] Available at: <https://www.nao.org.uk/wp-content/uploads/2019/01/Investigation-into-the-management-of-health-screening.pdf>.

33 UK Parliament. 2019. Public Accounts Committee - Adult Health Screening Inquiry. 20 Mar 2019 [ONLINE] Available at: <https://www.parliament.uk/business/committees/committees-a-z/commons-select/public-accounts-committee/inquiries/parliament-2017/inquiry5/publications/>. [Accessed 17 September 2019].

34 Richards, M. 2019. Independent Review of National Cancer Screening Programmes in England. [ONLINE] Available at: <https://www.england.nhs.uk/wp-content/uploads/2019/02/independent-review-of-cancer-screening-programmes-interim-report.pdf>

35 UK Parliament. 2019. Treasury Minutes 'Government response to the Committee of Public Accounts on the Ninety-Third to the Ninety-Fourth and Ninety-Sixth to the Ninety-Eighth reports from Session 2017-19' CP151, P8-11 [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/819707/CCS207_CCS0719610434-001_Gov_response_to_Public_Accounts_on_the_93_-_98_reports_bookmarked.pdf

4. WHERE ARE WE NOW?

This chapter presents further detail on each of the five screening programmes considered as part of this review. These programmes are distinctive in that they require people to be actively called and recalled for screening as required.

INTRODUCTION

The five national programmes considered as part of this review involve different age ranges, population segments and frequencies of screening. They commenced at different points in time, but have each evolved and are all now similarly well established. They are each backed by a strong evidence base and administered through a highly committed workforce. Collectively, they provide a platform for research which is unrivalled internationally.

A summary on each programme is presented below, including an overview of how the programmes have evolved over time, their current performance, and anticipated changes that are in the pipeline.

Note: All costs set out in this chapter are as advised by NHS England and NHS Improvement based on latest actual 2018/19 expenditure and are stated pending publication of the Annual Accountability Statement for 2018/19.

ABDOMINAL AORTIC ANEURYSM SCREENING

Screening for abdominal aortic aneurysm (AAA) was introduced in 2013. It is targeted exclusively at men as they have a much higher risk of AAA than women. Men aged 65 are invited for a one-off ultrasound scan of their aorta. Depending on the diameter of their aorta they are either reassured (less than 3cm), invited to annual scans (3cm-4.4cm), invited to quarterly scans (4.5cm-5.4cm) or referred to a specialist surgeon within two weeks due to a high risk of rupture (5.5cm or more). In 2017/18, around 286,000 men aged 65 were invited to AAA screening of whom nearly 230,000 (80.5%) attended³⁶. The AAA programme is estimated to cost £14 million per year.

Randomised control trials (RCTs) have demonstrated the impact AAA screening has in reducing mortality of those screened^{37, 38, 39}. An article published in the Journal of Vascular Surgery in 2013 looked at the implementation of the

36 Public Health England. 2018. PHE Screening - AAA screening annual data for 2017 to 2018. [ONLINE] Available at: <https://www.gov.uk/government/publications/abdominal-aortic-aneurysm-screening-2017-to-2018-data>

37 Lindoldt J Juul S Fasting H Henneberg, E., 2002. Hospital Costs And Benefits Of Screening For Abdominal Aortic Aneurysms. Results From A Randomised Population Screening Trial. European Journal of Vascular and Endovascular Surgery, 23(1), 55-60.

38 Wilmink TB, Quick CR, Hubbard CS, Day, N., 1999. The influence of screening on the incidence of ruptured abdominal aortic aneurysms. J Vasc Surg, [Online]. 30 (2), 203-208. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/10436439> [Accessed 17 September 2019].

39 Ashton, H., 2016. The Multicentre Aneurysm Screening Study (MASS) into the effect of abdominal aortic aneurysm screening on mortality in men: a randomised controlled trial. Lancet, [Online]. 360 (9345), 1531-9. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/12443589>. [Accessed 17 September 2019].

AAA NHS screening programme and supported the findings of these studies⁴⁰. The authors anticipated that the programme would reduce the proportion of premature deaths by up to 50% and continue to remain cost effective. AAA screening may be modified in the future in response to changes in incidence (likely to relate to the reduced prevalence of smoking).

A detailed summary of the AAA programme can be found in **Appendix C**.

BOWEL SCREENING

The bowel screening programme has been offered to men and women aged 60 to 74 since 2006, with another one-off screening test offered to men and women at the age of 55 in some parts of England. Bowel cancer screening is estimated to save around 2,400 lives per year⁴¹. The bowel screening programme costs £211 million per year, excluding the costs of implementing the Faecal Immunochemical Test (FIT) and the continued roll out of bowel scope. There are two elements to the current programme:

- **Testing for occult blood in stools** At present, this is aimed at men and women aged 60 to 74, though the plan is to reduce the starting age to 50. Originally, this involved a Guaiac Faecal Occult Blood Test (gFOBT), but from June 2019 a more sensitive and simpler FIT has been introduced. The kits are sent to people at home every two years. Around 4.4 million people were invited for screening in 2017/2018, of whom 2.5 million people returned a sample (57.7% uptake)⁴².
- **Bowel scope** A single test aimed at men and women aged 55. In 2017/18, around 337,500 were invited to testing, of which around 155,600 underwent a flexible sigmoidoscopy (46% uptake).

Extension of the bowel screening programme has already been agreed in principle with the NHS Long Term Plan setting out a commitment to diagnose more cancer cases at an early stage by lowering the starting age from 60 to 50⁴³.

The UK National Screening Committee (UK NSC) also recommends improving the sensitivity of FIT by changing the threshold at which it is deemed positive. There is no doubt that this will lead to more cancers being diagnosed and to more polyps/adenomas, which could develop into cancer, being detected and removed. Workforce, including colonoscopy capacity is the rate limiting factor in implementing these changes. This is considered in further detail in Chapters 7 and 10.

A detailed overview of the bowel screening programme is set out in **Appendix D**.

40 Davis M, Harris M, Earnshaw, J., 2013. Implementation of the National Health Service Abdominal Aortic Aneurysm Screening Program in England. *J Vasc. Surg.*, [Online]. 57 (5), 1440-5. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/23523277>. [Accessed 17 September 2019].

41 Parkin, DM. (2008). Predicting the impact of the screening programme for colorectal cancer in the UK. *J Med Screen.* 2008;15(4):163-74. [ONLINE] Available at: <https://journals.sagepub.com/doi/full/10.1258/jms.2008.008024>.

42 Public Health England. 2018. Public Health Profiles - Cancer Services. [ONLINE] Available at: <https://fingertips.phe.org.uk/profile/cancerservices> <https://fingertips.phe.org.uk/profile/cancerservices>

43 NHS England. 2019. The NHS Long Term Plan. p.58

BREAST SCREENING

The Breast Screening Programme was established in 1988 and began offering women aged 50 to 64 triennial screening appointments. In 2000, the screening programme announced that it would be extended to include women aged 50 to 70 years old (seven rounds). Women who are over the age of 70 are able to self-refer for a screening appointment. In 2017/18, around 2.5 million women aged 50-70 were invited for breast screening, with around 1.8 million attending their mammogram appointment (71%) and 18,001 cancers were detected⁴⁴. The breast screening programme is estimated to cost £169 million per year.

Technology has improved over the years with digital imaging now being standard. Breast screening is estimated to save one life for every 1,200 women screened, or up to 1,700 lives per year⁴⁵.

The age range of people invited for routine breast screening may be extended if a current randomised controlled trial shows benefit, although this will not be known for at least another five years. Specifically, the trial is assessing the risks and benefits of an extra screening round, between the ages of 47-49 and separately, of offering up to three additional triennial screening invitations to women in the age range of 71-73 years old⁴⁶. A case study of this important research is set out in Chapter 11.

At present, the only nationally implemented targeted screening programme relates to women at high risk of breast cancer. In comparison with the population screening programme, this involves very small numbers of women (around 6,500) who undergo more intensive screening starting at an earlier age.

A detailed overview of the breast screening programme is set out in **Appendix E**.

CERVICAL SCREENING

The cervical screening programme was established in 1988 and is offered to women aged 25 to 64 (every three years to women aged 25 to 49 and every five years from the ages of 50 to 64). The programme is estimated to cost £185 million per year, including sample taking, laboratory costs and colposcopies.

It consists of 12 tests in a lifetime (assuming standard intervals and no additional tests needed). It started as a 'smear' test, then progressed to liquid based cytology and is now transitioning to primary HPV testing, with all services to have transitioned by December 2019. Cervical screening is estimated to save around 5,000 lives per year⁴⁷. 4.5 million women were invited for screening in 2017/18 of whom 3.18 million had cervical samples taken (71.4% uptake)⁴⁸.

44 Public Health England. 2018. Public Health Profiles - Cancer Services. [ONLINE] Available at: <https://fingertips.phe.org.uk/profile/cancerservices> <https://fingertips.phe.org.uk/profile/cancerservices>

45 Marmot, M., 2012. The benefits and harms of breast cancer screening: an independent review. *Lancet*, [Online]. 380 (9855), 1778-1786. Available at: <https://www.thelancet.com/action/showPdf?pii=S0140-6736%2812%2961611-0> [Accessed 17 September 2019].

46 NHS Breast Screening Programme. 2019. AgeX Trial, Cancer Epidemiology Unit, University of Oxford. [ONLINE] Available at: <http://www.agex.uk/ABOUT/>. [Accessed 17 September 2019].

47 Peto, J. (2004). The cervical cancer epidemic that screening has prevented in the UK. *The Lancet*. 2004; Jul 17-23;364(9430):249-56. <https://www.ncbi.nlm.nih.gov/pubmed/15262102>

48 NHS Digital, 2018. Cervical screening programme 2017-18. [ONLINE] Available at: <https://files.digital.nhs.uk/B1/66FF72/nhs-cerv-scre-prog-eng-2017-18-report.pdf>

The incidence of cervical cancer is expected to fall further as the effects of HPV vaccination start to emerge. Pilots of HPV self-sampling are due to start in two London areas soon in an attempt to increase participation amongst women who do not attend cervical screening⁴⁹. If successful, this should increase the uptake of screening by making the test more acceptable to a greater number of people. This is discussed in more detail in Chapter 7.

A detailed overview of the cervical screening programme is set out in **Appendix F**.

DIABETIC EYE SCREENING

Diabetic Eye Screening (DES) was introduced in 2003. The programme invites all people with diabetes aged 12 years and over for an annual screen of the back of their eye (retina and macula). 2.7 million people were invited to DES in 2017/2018, of whom 2.3 million people attended screening (82.7% uptake)⁵⁰. The DES programme is estimated to cost £85 million per year.

People with diabetes who are found to have retinopathy are either recalled sooner than one year or if severe, are referred to hospital eye services for further assessment and treatment. It is planned that the interval will be extended to two years for those with no evidence of retinopathy. A study carried out by Liew et al. compared the main causes of blindness in patients aged between 16 to 64 recorded in 1999/00 with 2009/10. It found that for the first time in five decades, diabetic retinopathy/maculopathy was not the major cause of blindness in working age people. The study suggests that the roll out of DES and better glycaemic control are contributing to the reduction⁵¹.

Modifications to the DES programme to increase the interval between screens have already been agreed in principle. A detailed overview of the programme is set out in **Appendix G**.

STRENGTHS AND CHALLENGES

It is clear that screening programmes have evolved in many ways over the past 30 years. New programmes have been started and existing programmes have been modified in response to developments in the evidence base, although not always as soon as would have been desirable.

Whilst each programme is broadly achieving its intended goal of reducing some mortality – or blindness in the case of the DES programme – each could undoubtedly also do better. Specific problems and challenges hinder their progress and performance, some of which are shared and some of which are unique. These include:

49 Pike, H., 2019. HPV self testing to be piloted in two areas. BMJ, [Online]. 364,1356. Available at: <https://www.bmj.com/content/364/bmj.11357> [Accessed 17 September 2019].

50 Public Health England. 2018. Annual 2017-18 Publication YPA KPI data. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/769453/Annual_2017-18_Publication_YPA_KPI_data_V1_NF.ods

51 Liew, C, Michaelides, M, Bunce, C., 2014. A comparison of the causes of blindness certifications in England and Wales in working age adults (16–64 years), 1999–2000 with 2009–2010. BMJ Open, [Online]. 4 (2), e004015. Available at: <https://bmjopen.bmj.com/content/4/2/e004015> [Accessed 17 September 2019].

- **Governance** Concerns about unclear governance have been raised frequently during the course of this review. This lack of clarity has contributed to delays in implementing changes which have been shown to save lives, including FIT for bowel screening and primary HPV for cervical screening. These delays have inevitably led to avoidable loss of life. It has been estimated that a one-year delay in implementing HPV screening would miss the opportunity to prevent nearly 600 cases of cervical cancer and lead to a loss of nearly 1,600 quality adjusted life years⁵². See Chapter 5.
- **IT** Information systems are particularly poor for breast and cervical screening but are also not unified for DES. Although the IT systems for the more recent programmes (bowel and AAA) are more functional, all five programmes have difficulties linking from end to end of the screening pathway (e.g. linking to GP systems before screening and to hospital systems after screening has been undertaken). As such, IT systems cannot support the safe running of screening programmes nor protect against missed opportunities to diagnose cancer and other disease. See Chapter 6.
- **Uptake and coverage** Uptake and coverage vary widely between the five programmes. Diabetic eye screening (DES) and abdominal aortic aneurysm (AAA) screening have the highest uptake, and bowel screening the lowest. Uptake/coverage for breast and cervical screening has been falling. This must be reversed. See Chapter 7.
- **Wider performance issues** In addition to uptake and coverage, other metrics relate either to patient experience or outcomes. Timeliness of sending results to patients following screening and of arranging onward assessment and treatment for those who need it are particularly important in this regard. See Chapter 8.
- **Financial incentives** Many screening programmes are currently provided through block contracts, which provide little incentive to providers to actively improve uptake. Financial incentives – such as moving to payments based on activity, targeted payments for enhanced services or enhancements to GP payment systems at either practice or primary care network level – could further increase uptake of screening and improve the quality of screening services. See Chapter 9.
- **Capacity** Each programme faces different capacity issues relating to workforce, equipment and facilities. Facilities and equipment (e.g. mammography equipment and mobile vans for breast screening) are often well over 10 years old and not fit for purpose. See Chapter 10.
- **Research** Academics often face long delays in getting access to the screening datasets they need to evaluate the impact of the screening programmes and to evaluate potential improvements. See Chapter 11.

Against a backdrop of future developments on the horizon as set out in Chapter 2, it is essential that these challenges are resolved so the system is well-equipped for the near, and not-so-near, future.

52 Journal of Medical Screening 2018 Oct 3; 26(1):44-49. Is a delay in the introduction of human papillomavirus-based cervical screening affordable? Available online: <https://journals.sagepub.com/doi/full/10.1177/0969141318800355>

5. GOVERNANCE

This chapter considers the fundamental issue of governance. Governance and accountability of screening programmes have evolved with the introduction of the 2012 Health and Social Care Act.

INTRODUCTION

A key focus of the Terms of Reference for this review was to consider the allocation of responsibilities between NHS England (NHSE)⁵³, Public Health England (PHE) and the Department of Health and Social Care (DHSC), and how effectively these translate screening policy into implementation. This includes how screening programmes should be commissioned, delivered, performance managed and quality assured.

The Independent Review of Breast Screening and the National Audit Office report on adult health screening raised significant concerns relating to the governance of screening programmes in England. This was echoed within the report of the subsequent Public Accounts Committee hearing which found that: *'It is unacceptable that the national oversight of screening programmes has failed, with the Department, NHS England and Public Health England all being too slow to recognise and respond to the problems this has caused'*.

These concerns have been reiterated by many individuals throughout the course of this review. A large number of respondents to the review have commented on the complexity of the current governance arrangements and have asked who is in charge of screening? The answer to that is currently unclear. This chapter starts by looking at:

- Governance up until 2012
- Current governance

It then breaks down the current approach to governance into seven core activities to examine the issues at each stage of the pathway and what can be done to address them:

- Horizon scanning and evidence reviews
- Making recommendations on screening for Ministerial decision
- Pilots
- Implementation
- Commissioning of services, though to oversight of delivery
- Audit and monitoring (see Chapter 11)

⁵³ Public Health Commissioning, under the Section 7a agreement, is a statutory responsibility of NHS England having been delegated by the Secretary of State for Health and Social Care. In this context, this report refers to NHS England rather than NHS England and NHS Improvement.)

GOVERNANCE UP UNTIL 2012

A useful starting point when considering the current governance of screening programmes is to first understand how this has changed through the introduction of the 2012 Health and Social Care Act⁵⁴.

Prior to the health service reforms, oversight of cancer screening programmes was the responsibility of a Director of Cancer Screening in the Department of Health, who reported to Ministers via a National Cancer Director. The Director of Cancer Screening was supported by advisory committees for the breast, cervical and bowel screening programmes. The diabetic eye screening (DES) screening programme and screening for abdominal aortic aneurysm (AAA) were the parallel responsibility of a Director of Non-Cancer Screening, also based in the Department of Health. Note that screening for AAA was not a fully operational screening programme at this point.

Funding for implementing major changes to existing programmes – or introducing new programmes – was negotiated by the Department of Health and only allocated once services were ready to take on the new activity. For AAA and DES, funding was allocated to the hosting NHS Trust (i.e. not formally commissioned through NHS contract processes). Funding for ongoing ‘business as usual’ services was included in primary care trust (PCT) budgets.

PCTs were generally responsible for commissioning screening services. Local Directors of Public Health worked closely with Strategic Health Authority (SHA) screening leads and generally had a very good understanding of screening and of the importance of engaging communities and primary care providers. These teams were downsized considerably when they moved to local authorities as part of the health service reforms.

Quality assurance services for cancer screening were regionally based, with concerns reported to Regional Directors of Public Health and the Director of Cancer Screening. Regional Directors of Public Health were responsible for acting on quality assurance reports. When necessary, these were also escalated to the National Cancer Director. When problems arose, these were tackled in conjunction with service providers and local commissioners whenever possible. On occasions, it was necessary to involve regional Directors of Public Health and SHA Chief Executives to resolve quality and performance issues. Cancer networks were also in place and helped to join up planning between symptomatic and screening services.

With DES, quality assurance was provided by a team of national advisors, working closely with Regional Directors of Public Health. A national quality assurance lead for the programme was in turn responsible to the national Director of Screening. Issues identified through quality assurance or investigations following a screening incident were supported by this team and led by SHA and PCT screening leads working with NHS Trusts. Rollout of AAA screening was completed in 2013 and as such quality assurance had not started at this point.

54 [legislation.gov.uk. 2012. Health and Social Care Act 2012. \[ONLINE\] Available at: http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted. \[Accessed 17 September 2019\].](http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted)

CURRENT GOVERNANCE

General responsibilities

DHSC is the overall steward of the system. Since 2013, expertise on screening has largely resided with PHE, while NHSE has been responsible for commissioning and the performance management of delivery.

Decisions on population screening programmes are currently made by Ministers and are set out in and funded through Section 7A (S7A) arrangements⁵⁵ and as part of NHSE's overall financial settlement. The UK National Screening Committee (UK NSC), supported by PHE, provides DHSC, the NHS in England, and the devolved administrations with expert evidence and advice on changes to screening programmes and the addition of new screening programmes. PHE then leads on tasks such as piloting changes and developing service specifications⁵⁶, working with NHSE as required. PHE is held to account for its responsibilities in relation to screening through its Quarterly Accountability Meeting with DHSC.

The Secretary of State for Health and Social Care holds NHS England to account for how well it performs its responsibilities to drive improvement in S7A services and to commission high quality public health services in England. NHSE in turn holds providers to account to ensure that they deliver the contracts that have been agreed in line with the programme service specification. NHSE can only commission screening services from primary and secondary care providers who are registered with the Care Quality Commission. Since the health service reforms, local authorities have had no formal role but have retained some expertise.

An overview of the current approach is set out overleaf. Other Arm's Length Bodies are also involved in issues which affect screening as follows:

- Health Education England (HEE) provide workforce planning to ensure current and new screening programmes have a highly skilled workforce to deliver programmes that meet the service specifications and quality assurance standards.
- The National Institute for Health and Care Excellence (NICE) provide clinical guidance on targeted screening programmes such as screening women with increased risk of breast cancer due to their family history.
- NHS Digital (NHSD) provide aspects of the information systems for various screening programmes including AAA, bowel, breast and cervical programmes, which support the invitation of people to screening, manage the process and record the results. This is considered in more detail in Chapter 6.

55 Department of Health and Social Care. 2018. NHS public health functions agreement 2018 to 2019. [ONLINE] Available at: <https://www.gov.uk/government/publications/public-health-commissioning-in-the-nhs-2018-to-2019>.

56 Public Health England. 2018. PHE Screening - Guide to 2018/19 screening specifications. [ONLINE] Available at: <https://phescreening.blog.gov.uk/2018/10/11/guide-to-2018-19-screening-specifications/>. [Accessed 17 September 2019].

- The Care Quality Commission (CQC) regulates primary and secondary care providers who deliver screening services. However, CQC has not to date incorporated findings from screening quality assurance into its assessments of providers.
- NHSX now provide strategic leadership for the provision of information systems for screening services following their establishment in May 2019.

ORGANISATIONS INVOLVED IN DELIVERING SCREENING PROGRAMMES



Source: Based on diagram in NAO's Report into Management of Adult Screening Services, February 2019.

Meetings and committees

The split governance results in a plethora of national and sub-national governance committees and meetings across PHE, NHSE and DHSC. These provide advice on screening programmes and contribute to oversight of delivery of screening at national and subnational levels. This can be confusing and lead to uncertainty about roles. This lack of clarity is felt more at the lower levels of the governance structure.

Current meetings include:

- A S7A Assurance Meeting which brings together senior officials from DHSC, PHE and NHSE. This is the formal accountability meeting for NHSE in its delivery of all S7A services, which is in turn supported by an informal tripartite directors meeting.
- Committees which provide advice on adult screening, including the UK NSC and its sub-committees (the Adult Reference Group and the Foetal, Maternal and Child Health Reference Group). Advisory committees are also in place for each of the individual programmes, as well as numerous subcommittees for individual aspects of each programme (e.g. colposcopy for cervical screening). While expert advice is clearly vital, many of the experts are unclear about their role or whether their advice is listened to.
- A Public Health Oversight Group led by NHSE, which provides oversight of commissioning and delivery across screening and immunisation programmes and is supported by recently established individual programme boards for the breast, bowel, cervical and DES screening programmes.
- Further local programme boards then bring together the NHSE commissioning teams (including embedded staff from PHE), representatives of the screening quality assurance service (SQAS) and providers. These are variably organised in different parts of the country.

The next sections of this chapter consider the different stages of the governance process and issues which occur in each.

HORIZON SCANNING AND EVIDENCE

With support from PHE, the UK NSC maintains a watch on emerging evidence for possible new population programmes or modifications to existing programmes. It also invites proposals for new programmes from stakeholders (professionals and the public). When these are considered to have merit, formal evaluation of evidence of effectiveness is undertaken together with assessment of the potential cost effectiveness, often based on modelling. This is an important function but the UK NSC only recommends approaches which apply to whole segments of the population, excluding potential programmes that would be targeted at high risk groups.

Concerns have been expressed during the course of this review that the horizon scanning function is not as forward looking or timely as it might be. An example is set out in the Faecal Immunochemical Test case study set out later in this chapter.

MAKING RECOMMENDATIONS ON SCREENING FOR MINISTERIAL DECISION

Following this formal evaluation, recommendations on national population screening programmes are made by the UK NSC to Ministers in each of the four UK countries, based on evidence of clinical and cost effectiveness. These recommendations cover antenatal, new born and child health screening and young people and adult health screening. PHE host the secretariat for the UK NSC.

In England, the recommendations must then be approved by the Secretary of State for Health and Social Care. NHSE then becomes responsible for implementation, with funding agreed by the DHSC and provided via a ring-fenced budget (S7A). Timescales for implementation are also agreed.

Recommendations on targeted screening programmes are made separately by NICE within some clinical guidelines, based on the evidence of clinical and cost effectiveness (see examples given in Chapter 2). These are published as guidelines for clinical commissioning groups (CCGs) but their implementation is not nationally mandated. As a local responsibility, there is also no ringfenced funding to support implementation and costs are expected to be covered through allocations outside of the S7A ringfence, primarily general CCG funding allocations.

This separation of approach between targeted and population screening of functions is widely considered to be an unhelpful historical anomaly. Given the future importance of targeted screening approaches, a new approach is needed which brings together the consideration and funding of population and targeted screening approaches as key national priorities.

PILOTS

For any new programme or major modification to an existing programme, large scale pilots may be required to assess how the findings from randomised control trials translate into NHS practice. These can usefully address practical issues such as testing the acceptability of the screening concerned, and considering workforce, training, IT and equipment requirements alongside performance metrics and funding issues. For some programmes, the UK NSC will recommend pilots before making their final recommendation.

Pilots have historically been run by PHE. This approach means that issues which may be essential to full implementation of a screening programme have sometimes not been fully considered and can lead to delays (e.g. unintended consequences to related pathways; source of existing funding needing to be moved). The current Lung Health Check pilots have been separately sponsored outside of these arrangements by NHSE as set out in Chapter 2.

Case study: Implementation of the Faecal Immunochemical Test

A report to the UK NSC on the pilots of the Guaiac Faecal Occult Blood Test in 2003 recommended that immunochemical tests should be considered. European guidelines were published in 2011 and pilots of the Faecal Immunochemical Test (FIT) were undertaken in England in 2014. The UK NSC made its recommendation on FIT in 2015.

A service specification for FIT was developed by PHE, but a business plan was not. Consequently, uncertainty has remained around endoscopy requirements (workforce and endoscopy suites), procurement of laboratory services, impact on histopathology and financial consequences of implementation at different levels of sensitivity of FIT.

This lack of initial horizon scanning – and later planning – caused significant delays in implementation. Had the recommendation been made sooner, and more consideration paid at an earlier stage to implementation requirements, more people could have been benefited from this test at an earlier stage. By comparison, FIT was introduced in Scotland in November 2017.

Case study: Primary human papillomavirus (HPV) testing

The introduction of primary HPV testing requires a major reduction in the number of laboratories across the country, from 46 to eight or nine. This affects approximately 1,100 staff. This has created challenges for transition, resulting in major delays in women receiving results and tests. The division of responsibilities between PHE and NHSE has exacerbated these difficulties.

IMPLEMENTATION

The phase following piloting and approval by the Secretary of State includes a range of activities including:

- Development of a business case
- Developing specifications for services
- Developing information materials for the public and health professionals
- Deciding on the optimal shape of services across the country (e.g. size and number)
- Determining workforce requirements and training where necessary
- Commissioning service providers
- Commissioning equipment
- Developing IT systems

Responsibility for the different elements of implementation has tended to be divided between PHE (who are responsible for the development of the service specifications upon which the commissioning of services is based) and NHSE (who are responsible for other aspects of implementation, with input from HEE and NHSD). This has led to confusion and delays. When asked whether it makes sense to have two different organisations overseeing delivery, respondents to this review have generally answered 'no'.

COMMISSIONING OF SERVICES AND OVERSIGHT OF DELIVERY

The key components for the 'business as usual' phase include:

- Commissioning of local services (and recommissioning where necessary)
- Monitoring of performance of individual providers
- Quality assurance and quality improvement
- Ensuring action is undertaken to improve uptake and quality of services
- Investigating and managing incidents
- Ensuring coherence between screening and other relevant services
- Aggregating information and reporting at regional and national levels

Further detail on each of these is set out below.

Governance at a national level within NHSE has been reformed this year with the establishment of a dedicated Director of Public Health Commissioning and Operations alongside the establishment of the national programme delivery boards and a refresh of the Public Health Oversight Group membership.

However, the current tripartite governance arrangements create challenges along the screening pathway. The current system lacks clear leadership and accountability. The rationale for dividing responsibilities across PHE and NHSE is often unclear and creates confusion, delays and risks to patient safety. There is a pressing need to simplify governance and improve accountability, ownership and oversight.

Commissioning of local services (and recommissioning where necessary)

Governance at a subnational level within NHSE has also been reformed this year. Screening programmes are now led by new regional Directors of Commissioning supported by new regional Directors of Primary Care and Public Health Commissioning and alongside the existing NHSE Heads of Public Health Commissioning. They are in turn supported by screening and immunisations teams comprising staff embedded from PHE. Overall accountability for performance sits with the NHSE Regional Director.

Each region has its own set of programme boards for overseeing performance and quality and there is considerable variation across the country regarding their membership, scope and function. This often leads to confusion around

where responsibilities lie. Many boards are run by screening and immunisation teams, with Heads of Public Health Commissioning dealing with contractual issues, often escalated from the programme boards.

As the new regional structure and operating model embeds more fully, the opportunity to drive greater consistency and improvements across local areas must be realised. Regional Directors should be held to account on addressing screening performance issues, and risks regarding the implementation of new programmes, or changes to existing programmes. Key to this is cohesive national and regional governance structures. This includes clarification of the role of NHS Regional Directors of Public Health who are now members of the NHSE Regional Executive team.

At present, PHE is responsible for national 'programme' teams for each of the screening programmes and for the SQAS, which are regionally based. PHE also has staff embedded within the NHSE local commissioning teams. This means that much of the expertise on screening resides within PHE employed staff, while much of the responsibility for overseeing delivery resides with NHSE.

This results in a fairly crowded and complicated local governance organisational structure: PHE embedded screening leads, NHSE local commissioners and the SQAS work in various degrees of integration across the country, but in some places, as three separate entities. Although staff from the two organisations try hard to work well together, there is undoubtedly a 'them and us' culture.

Quality assurance and quality improvement

Whilst respondents to this review may have questioned the logic of having two separate organisations responsible for delivery, many have similarly considered that the quality assurance function is vital and must be protected. Some have suggested that it should be protected by being hosted by a separate organisation from that overseeing commissioning, whilst others have reported that they want to work ever more closely with commissioning teams and that separation is a disadvantage.

SQAS does indeed have a vital role both in quality assurance and quality improvement. In addition to undertaking inspections of providers, they work closely with providers and commissioners to provide advice and to help drive quality improvement. Whilst a national service, SQAS is regionally organised with teams relating to each screening programme. It also investigates local incidents. Expertise within SQAS often exceeds that of others involved in oversight or commissioning of screening programmes.

Investigating and managing serious incidents

Guidance to providers of local NHS screening services in England is available on managing safety incidents in NHS screening programmes and sets out the roles of each organisation in the process, based on the NHS England Serious Incident Framework⁵⁷. In practice however, its implementation appears variable.

57 Public Health England, 2017. Managing Safety Incidents in NHS Screening Programmes. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/672737/Managing_safety_incidents_in_National_screening_programmes.pdf

PHE investigates serious incidents occurring in screening programmes and collates (but does not publish) information on less serious incidents. In line with standard emergency preparedness, resilience and response procedures, NHSE manages serious incidents and investigates where these relate to issues for which it is responsible whilst NHSD supports investigation of incidents when it relates to the National Health Application and Infrastructure Services suite of systems and core demographic services.

Under the current arrangements, it is not immediately obvious which organisation should take the lead on investigating serious incidents. This creates an environment in which no one person, or organisation, has a clear overview of the system as a whole.

There have been two national incidents reported widely in the last few years, and around 500 less serious incidents last year. These are discussed at a local level, and information is escalated to PHE nationally. These are not currently publicly reported and indications through the work of this review are that this information has not always been shared with NHSE nationally. Opportunities for learning are therefore missed.

Ensuring coherence between screening and other relevant services

Screening does not exist in isolation. Some of the diagnostic services (e.g. breast assessment, colonoscopy and colposcopy) overlap with those for patients presenting symptomatically. If found to have cancer following screening, patients need to be referred without delay to multidisciplinary cancer teams. Similarly, people found to have significant aortic aneurysms need to be referred to vascular surgery services and people with diabetes found to have significant retinopathy need to be referred urgently to hospital eye services. Engagement between commissioners of screening services and those commissioning symptomatic services is currently variable. The different commissioners for these services need to work more closely with each other to ensure that pathways are managed effectively and that any capacity barriers are dealt with. Further information on this issue is set out in Chapter 10.

Aggregating information and reporting at regional and national levels

The split of responsibilities also manifests itself in the publishing of data which is essential for performance management. NHSE reports nationally on S7A key performance indicators, whilst PHE collates data on a much wider set of public health indicators. PHE analyse this data, including provider activity data, and provide national reports to NHSE under a Memorandum of Understanding but this is often months out of date. Although, in some cases data sharing is done in a timely fashion, overall this makes effective and timely operational and programme management challenging. The difficulty the review team has had in getting data to support its activity exemplifies this.

Audit and monitoring

This function is set out in further detail in Chapter 11.

RECOMMENDATIONS

This review recommends that:

- Recommendation 1:** The Chief Medical Officers of the UK should bring together an advisory group to agree Terms of Reference for a new single screening advisory body. These terms of reference should be kept under regular review. This screening advisory body should cover both population and targeted screening, have an effective horizon scanning function, undertake and commission evidence reviews, and model impact and cost effectiveness.
- Recommendation 2:** Recommendations on targeted screening should be given the same weight and funding commitments as those for population screening and should be commissioned through the S7A agreement according to nationally agreed standards and service specifications.
- Recommendation 3:** NHSE and PHE should produce a roadmap for the transfer of relevant staff with expertise on screening delivery from PHE to NHSE to support their respective future roles. This roadmap should also consider how NHSE would integrate the delivery of targeted and population screening.
- Recommendation 4:** Following decisions by Ministers, NHSE should assume sole responsibility for the delivery of screening programmes, appointing a named director responsible for screening, so that it is clear to all stakeholders who is in charge. This should include both the implementation of Ministerial decisions on screening and 'business as usual' matters, including commissioning, performance management, monitoring and audit. NHSE should work closely with PHE on the advice, NHSX on IT implementation and HEE in relation to workforce.

- Recommendation 5:** The screening quality assurance service which is currently accountable to PHE should also transfer to NHSE but should be ring-fenced as part of the S7A mandate. Local quality assurance reports and a national overview report should be published annually. These reports should be shared with the CQC to inform assessments of screening service providers, with CQC taking enforcement action to address quality issues where required. This would align the quality assurance processes with those for the rest of NHSE commissioned services.
- Recommendation 6:** NHSE should publish an annual report on population and targeted screening performance. This should include progress on extension and improvements to existing programmes and implementation of new programmes, high level metrics and summary information on incidents and other quality parameters. More detailed reports should be published on each of the individual programmes.
- Recommendation 7:** At national level, NHSE should consider how to build on existing programme board arrangements to deliver its accountability for delivering both population and targeted screening programmes. Arrangements should incorporate expertise from PHE, NHSX, NHSD, HEE and NHSE regions and other directorates as required.
- Recommendation 8:** Local commissioning of both population and targeted screening should be aligned with the new regional structure of NHSE. Regional Directors should be accountable for the screening functions within their geographical areas and should ensure delivery against key performance indicators.
- Recommendation 9:** NHSE should consider how to improve and standardise local oversight of population and targeted screening, bringing together the current expertise from the quality assurance and commissioning teams. These teams will need to work closely with commissioners on relevant services for patients who present symptomatically (e.g. mammography, endoscopy, colposcopy and hospital eye services). Local commissioning teams should be aligned as far as possible with Sustainability and Transformation Partnerships / Integrated Care Systems. This would be assisted by proposals for planned legislation to enable national and local commissioners to work together.

Recommendation 10: Local commissioners should work closely with cancer alliances, local authorities, and emerging primary care networks to ensure close join-up at local level, particularly where planned implementation of screening will impact on related service delivery. An example of this is the expected temporary increase in the number of colposcopies needed as a result of the move to primary HPV testing within the NHS cervical screening programme.

6. INFORMATION SYSTEMS

Information systems to support screening currently sit in an over-complicated landscape which hinders the delivery of screening programmes. Although the IT systems for bowel and abdominal aortic aneurysm screening are more modern than those for the other adult screening programmes, none have the full functionality required now or for the future. Replacement of systems to support breast and cervical screening is particularly urgent.

HOW DO IT SYSTEMS CURRENTLY WORK?

Current information systems for screening can be considered as having three broad components:



The overarching 'system' should be able to integrate information across these three components to provide 'end to end' information about screening both for an individual and for populations. In addition, information systems should be able to integrate information from different screening programmes (e.g. to assess whether individuals who do not participate in one screening programme are also non-attenders for other programmes) and with other health related information (e.g. immunisation history).

PROBLEMS WITH THE CURRENT SYSTEMS

The array of information systems currently in use to support the screening programmes presents numerous issues:

Identification

Different systems have been developed for the different screening programmes to extract demographic data from GP systems or the National Health Application and Infrastructure Services (NHAIS) suite of systems. These include Breast Screening Select and GP2DRS for diabetic eye screening (DES). However, some information which could enable service providers to contact invitees more easily (such as mobile phone numbers for text messaging) is not routinely extracted.

The systems similarly do not extract the clinical information which would be needed for some risk stratified screening programmes. Examples include: HPV vaccination history for cervical cancer screening; HbA1C blood test measurements as a measure of recent diabetic control for DES; and smoking history for possible lung cancer screening.

Managing screening

The more recent screening programmes (namely, bowel and abdominal aortic aneurysm) have single IT management systems that cover the whole country. This means that any updates to the system can be managed centrally and the screening record will follow the patient if they move from one part of the country to another.

In contrast, the breast, cervical and DES IT systems exist in multiple versions, effectively one per provider. As to be considered further in Chapter 10, these systems are often given low priority within NHS Trusts. Indeed, anecdotal evidence provided through the course of undertaking this review suggests that some breast screening management systems had not been updated following the Wannacry cyber-attack in 2017, despite the IT provider having developed a patch.

Having multiple versions of a system also means that transferring information to follow a patient who moves address is often delayed or, in the case of DES, may not be done at all. Similarly, it is a highly complex task to transfer information on relevant patients to a new provider when needed.

These individual systems are also old and liable to fail. In practice, this means that a system can be out of action for one or two days necessitating manual workarounds which are liable to human error and can pose risks to safety.

Recording outcomes

Information on outcomes for patients who have abnormal findings on screening tends to be held on myriad hospital systems (e.g. colposcopy, colonoscopy, histopathology, cancer management, ophthalmology and vascular surgery systems). While all of these systems are needed, it is important that interoperability with the screening systems is achieved.

Recent IT system development work has been undertaken by Public Health England (PHE), NHS England (NHSE) and NHS Digital (NHSD) to scope out and recommend changes for breast and cervical screening IT systems, resolve the differences between the Patient Demographic Service (PDS) and NHAIS and develop a strategic screening platform for screening IT. Historically however, the complex division of funding, decision-making and delivery of IT screening systems across multiple organisations and a lack of a coherent, long term strategic vision has meant efforts to improve current systems have at times been slowed, stopped or duplicated.

See **Appendix H** for further detail.

NEW STRATEGIC LEADERSHIP FROM NHSX

Since the publication of the interim report, there has been important progress in addressing some of the challenges posed. It is very welcome that NHSX – which brings teams from the Department of Health and Social Care (DHSC) and NHS England and NHS Improvement together into one unit to drive digital transformation and lead policy, implementation and change – have adopted screening IT systems as one of their flagship programmes⁵⁸. With planned investment of more than £1 billion a year nationally and a significant additional spend locally, there is major opportunity for NHSX to provide the strategic leadership to significantly improve and transform IT for screening programmes, in turn contributing to the required improvement in uptake and coverage, reducing the administrative burden on clinicians and readying the system for advances in screening practices.

It is widely agreed that IT systems for breast and cervical screening are in the most urgent need of renewal. The ‘discovery’ phase for developing new systems for these programmes has completed and has identified multiple inefficiencies, opportunities for error and corresponding benefits that will accrue from a new system.

NHSX, working closely with PHE, NHSE and NHSD, is now taking forward the initial (‘alpha’) development phases for both of these programmes. Each alpha stage will run for 6-12 weeks, after which the main (‘beta’) development work will commence. It will be important to progress this work programme at pace, under close scrutiny.

58 Department of Health and Social Care. 2019. Technology in the NHS - NHSX: Giving patients and staff the technology they need. [ONLINE] Available at: <https://healthtech.blog.gov.uk/2019/06/24/nhsx-giving-patients-and-staff-the-technology-they-need/>. [Accessed 17 September 2019].

FURTHER FUNCTIONALITY

Much needed functionality is lacking in the current approach. Personalisation is particularly key. A modern IT system should enable patients to make or change their own appointments for screening, to be able to access information on their own screening records and to see when their various screenings are next due. None of these functions are currently available.

The development of screening IT systems should include a necessary focus on the functionality needed to support improvements in uptake and coverage of screening (i.e. how we identify and invite people to be screened, manage them through the system, and analyse and review the results) as set out in the diagram below. It should also take into account the needs of both population and targeted screening, as well as the specific requirements of the trans and gender diverse population as set out in Chapter 7.

For the person being screened	For the clinician	For the service manager
<ul style="list-style-type: none"> • The right invite, at the right interval, with the right information • The ability to book own appointments online at a variety of locations and times • Text/email reminders • Ability to access screening record online • Reasonable adjustments for disabilities • Get test results and referrals as soon as possible • Records move with you 	<ul style="list-style-type: none"> • All patients identified • Call and recall function automated • Flexibility to change appointment times • Full patient information at their fingertips • Easy to share patient information with other clinicians working in different care settings across the length of the pathway • Minimal bureaucratic burden around data input and sharing, no manual workarounds • Able to view own performance data for revalidation purposes • Effective referral pathways across system 	<ul style="list-style-type: none"> • Data and reporting to monitor performance and quality assure service (e.g. coverage, uptake, key performance indicators, quality standards, timeliness, inequalities and outcomes) • Ability to publish timely reports to commissioners, providers, public and Members of Parliament • Interoperability of systems • A system of updating the IT so changes in technology (texts, e-reminders, genomics, artificial intelligence, stratification according to risk) can be introduced promptly and economically

Data is also needed by commissioners to adequately monitor, track and respond to performance. Fragmentation of current information systems makes data extraction difficult, and affects the ability to effectively oversee and quality assure services (e.g. monitoring the effectiveness of call and recall, or examining

variations in regional performance). This in turn makes it harder to drive improvements in performance and hold providers to account. Data will also be key to developing future risk stratification approaches.

RECOMMENDATIONS

This review recommends that:

Recommendation 11: NHSX should set out a roadmap for the delivery of new targeted and population screening IT systems as soon as possible, with a primary focus on the challenges with cervical and breast screening programmes and with regular reports on progress provided to DHSC and NHSE.

Recommendation 12: This review recommends that the development of screening IT systems should include a necessary focus on the functionality needed to support improvements in uptake and coverage of screening and take into account the specific needs of population and targeted screening approaches.

7. UPTAKE AND COVERAGE

This chapter examines the issues of uptake and coverage. An international trend is emerging that, in both breast and cervical screening programmes, a decreasing proportion of eligible women are being screened. This slow decline is a major concern. Evidence suggests that these declines can and should be halted and reversed.

INTRODUCTION

Any screening programme can only achieve its goals if a significant proportion of the relevant population choose to participate. Participation rates are measured through:

- **Uptake:** The proportion of those invited who take up the invitation to participate.
- **Coverage:** The proportion of the eligible population who have been screened within a given time period.

Both metrics matter. Uptake reflects the willingness and ability of the public to respond to an invitation to be screened. If uptake falls, coverage will fall. Coverage will also fall if the programme fails to invite all eligible people or if the intervals between screens are prolonged beyond those planned.

Uptake and coverage vary widely between the five programmes. Diabetic eye screening (DES) and abdominal aortic aneurysm (AAA) screening have the highest uptake, and bowel screening the lowest. Coverage for breast and cervical screening is intermediate, and worryingly is falling for cervical screening in particular. Although little cross-programme research has been undertaken, factors likely to account for low or high uptake and coverage include:

- **Acceptability:** Acceptability of the test to the person being screened is a key factor. AAA screening, which has high uptake, is a non-invasive procedure. Mammography and cervical sampling on the other hand, have lower uptake and are considered intrusive and uncomfortable.
- **Awareness:** Awareness of the benefits of the screening – and the corresponding risks of mortality/morbidity – almost certainly also plays a part. The spike in the uptake and coverage of cervical cancer screening following the death of Jade Goody in 2009 is a notable example of this, reflecting increased awareness at that time. High attendance rates for DES also reflect higher awareness of need amongst people with diabetes, who know that blindness can be a complication of their condition but can be avoided through early treatment.

- **Convenience:** The extra screening sessions that were needed following the breast cancer incident in 2018⁵⁹ were often provided in the evenings or at weekends. Screening providers report that many women welcomed this and wished it had been available previously. At present, most screening programmes are not organised to promote convenience for patients.
- **Accessibility:** A recent report by Jo's Cervical Cancer Trust⁶⁰ has shown that people with physical disabilities can find it hard to access cervical screening. Wheelchair access is also difficult on some older mobile vans for breast screening.
- **Reminders and endorsements:** Randomised controlled trials (RCT) have shown text reminders and endorsements by GPs to be effective in increasing uptake (see Chapter 11). To date, text reminders in particular, have been variably implemented across the country and across programmes.

INTERNATIONAL COMPARISONS

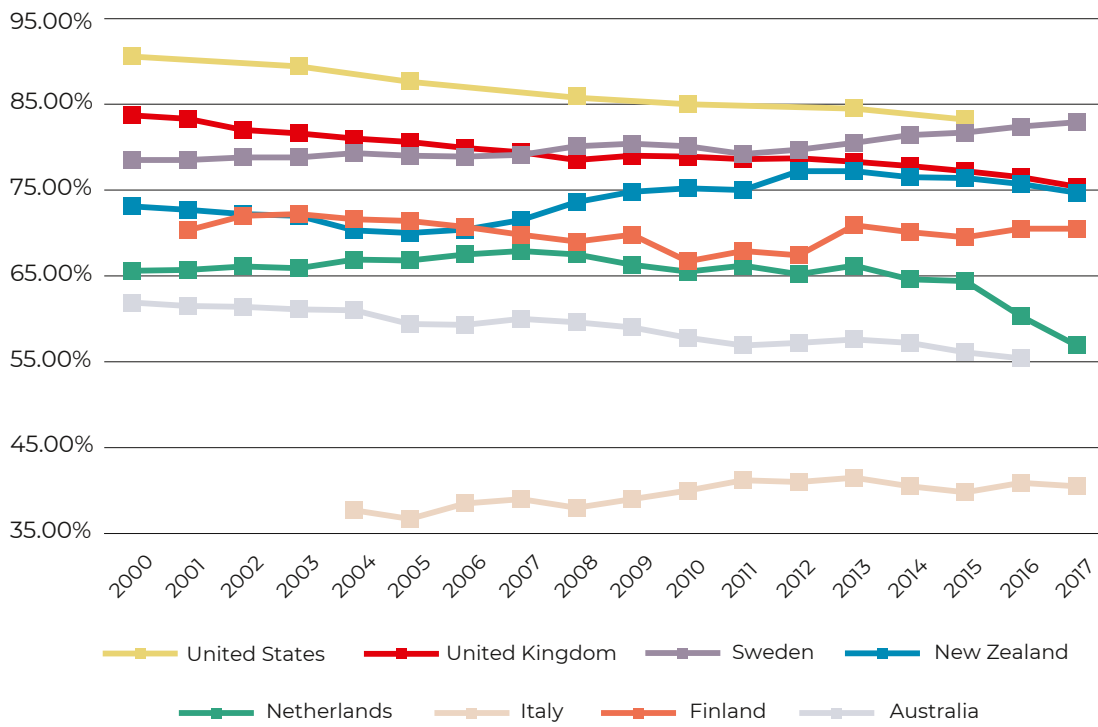
A slow fall in coverage for breast and cervical cancer screening has been observed in several high-income countries. Compared to other countries, the UK's performance on breast screening is in the middle of the 'pack'. The following charts present international performance comparisons for the UK, highlighting countries which are judged to be most comparable to the UK. Countries supply the Organisation for Economic Co-operation and Development (OECD) with survey data and programme data.

Note: Where possible, programme data is used in these graphs, and survey data is used only where there is no programme data available. For breast screening, Sweden and the USA supply survey data out of the countries included below. For cervical, only the USA supplies survey data out of the countries included in this comparison. There is no clearly comparable data for the AAA and DES programmes. Data for breast and cervical programmes undertaken internationally are shown.

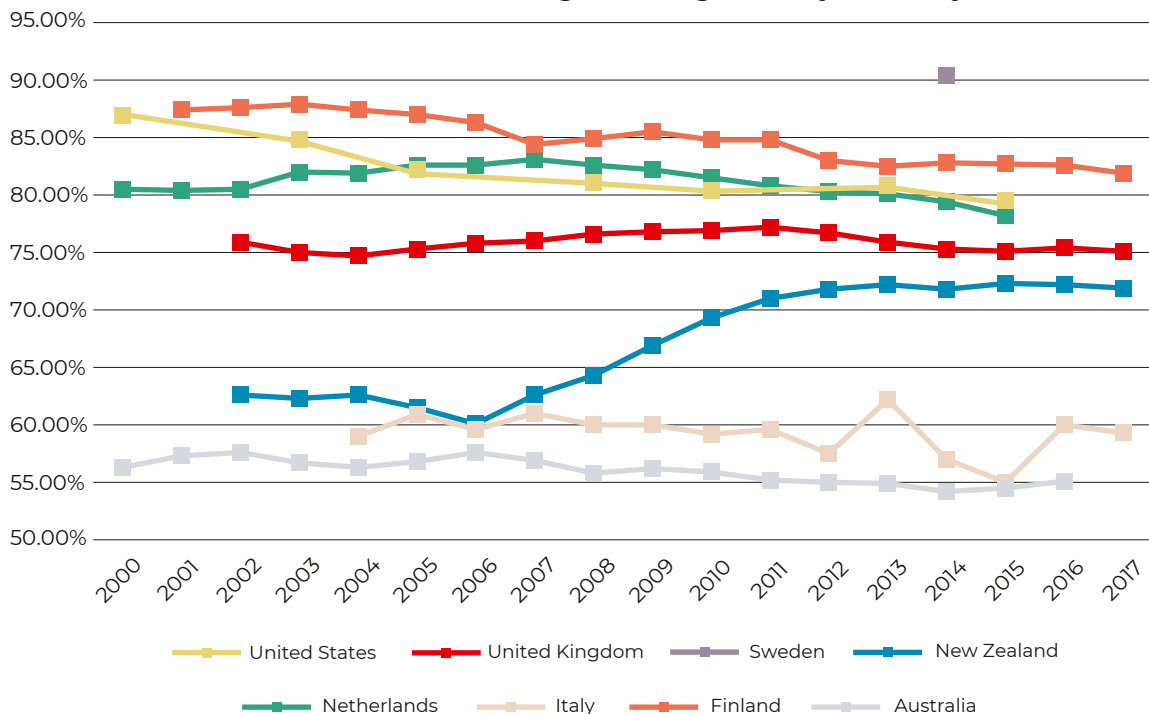
59 UK Parliament. 2018. House of Commons Hansard - Breast Cancer Screening.

60 Jo's Cervical Cancer Trust. 2019. Barriers to accessing cervical screening for. [ONLINE] Available at: https://www.jostrust.org.uk/sites/default/files/jos_physical_disability_report.pdf.

Cervical cancer screening coverage - % by country



Breast cancer screening coverage - % by country



Source: OECD⁶¹

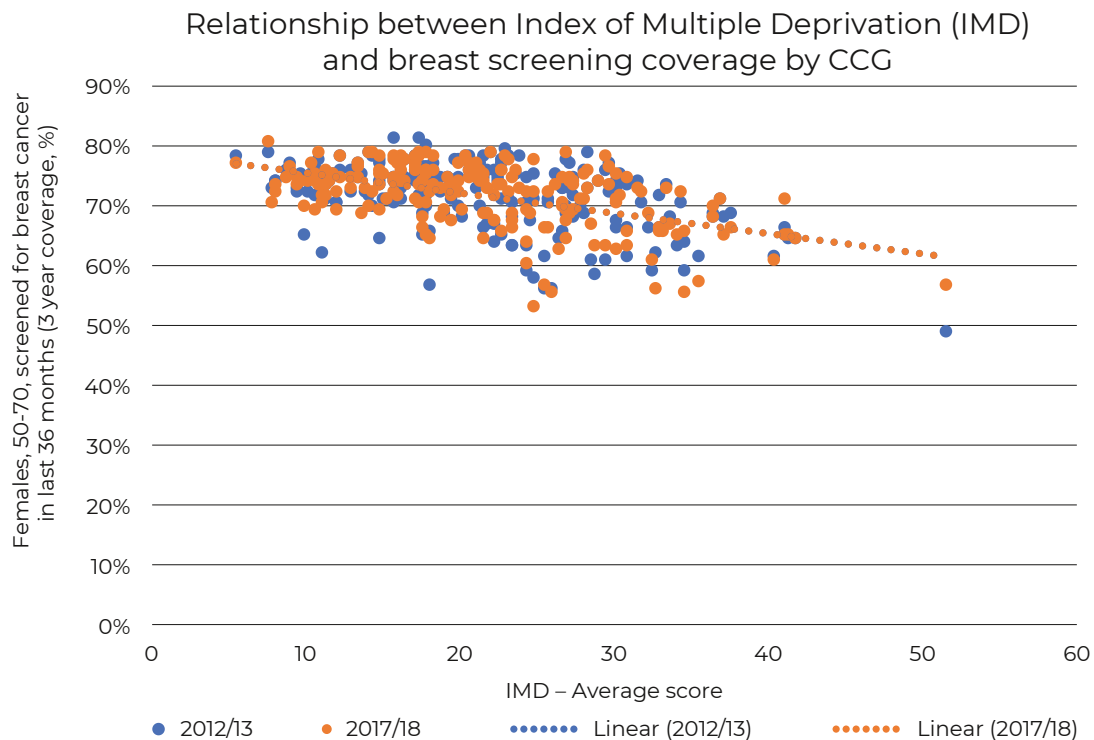
61 OECD, (2019). Health Care Utilisation: Screening. [ONLINE] Available at: <https://stats.oecd.org/index.aspx?Queryid=30159> [Accessed, 1 May 2019]

TARGETS AND STANDARDS

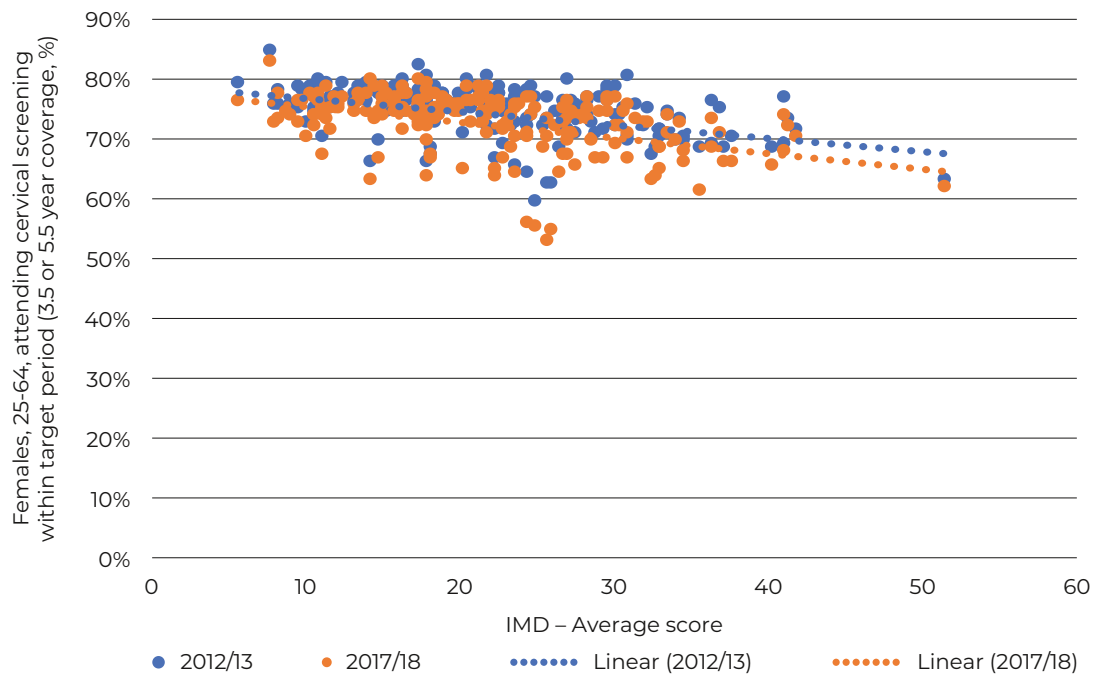
At present, two levels of performance on uptake and coverage are set for each screening programme. These are proposed by Public Health England (PHE) as part of the service specification and are agreed with the Department of Health and Social Care and NHS England as part of the Section 7A (S7A) annual agreement negotiation process. The lower threshold target represents the lowest level of performance that screening programmes are expected to attain. The 'standard' (higher) target represents the aspirational goal that it is thought could be achieved.

It is important to note that demographic factors and levels of affluence, deprivation and ethnic diversity affect uptake and coverage across the programmes. A large proportion of the variations observed at a local authority or clinical commissioning group (CCG) level can be attributed to these factors.

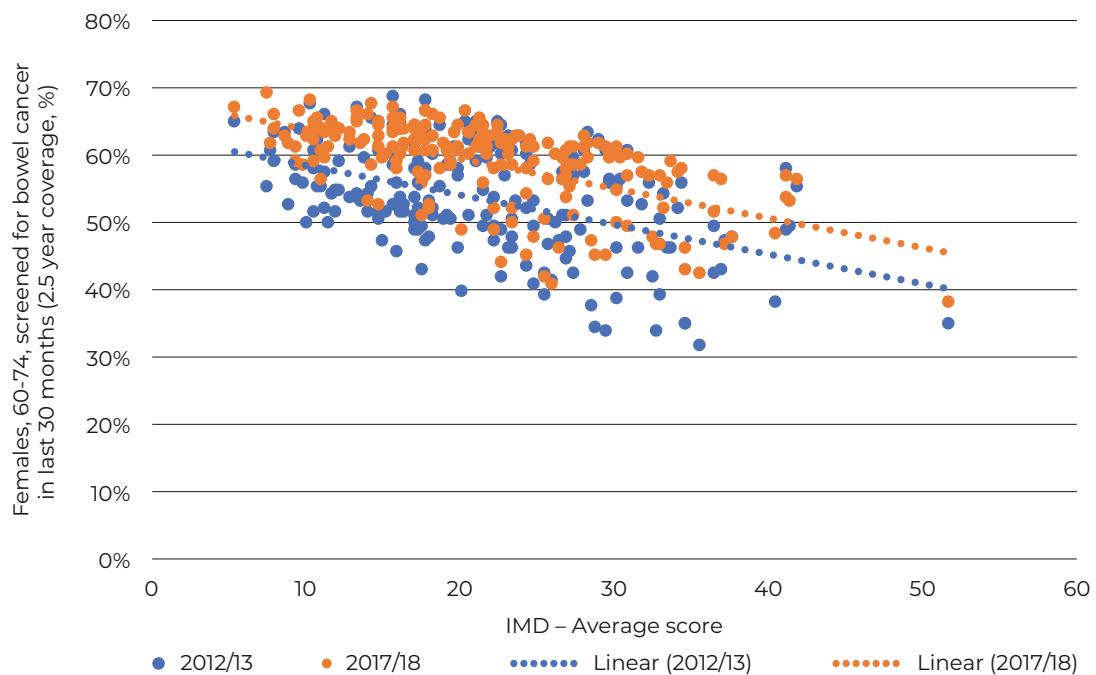
The following charts demonstrate the correlation between the average level of affluence/deprivation and coverage at CCG level for the breast, cervical and bowel screening programmes. In each programme, CCGs with higher levels of deprivation have lower coverage. In addition, the different colours in the graphs represent results for 2012/13 (blue) and 2017/18 (amber). While there has been a slow decline in coverage for both breast and cervical screening, it has improved for bowel screening. Similar correlations are seen when looking at the average age within CCGs. CCGs with older populations tend to have higher coverage than those serving younger populations.



Relationship between IMD and cervical screening coverage by CCG



Relationship between IMD and bowel screening coverage by CCG



Strenuous efforts should be made in areas of low uptake to encourage participation. The potential to improve is starkly demonstrated through the findings of a recently published study which looked at uptake amongst 3,060 women aged 60-65, who were eligible for all three of the cancer screening programmes. This showed that only 35% participated in all three programmes, 37% in two, 17% in one and 10% in none⁶².

62 Rebolj, M., 2019. Concurrent participation in screening for cervical breast, and bowel cancer in England. *Journal of Medical Screening*, [Online]. 0 (0), 1-9. Available at: <https://journals.sagepub.com/doi/full/10.1177/0969141319871977>

PERFORMANCE AS AT 2017/18

The table below sets out the latest available performance against the standards currently in use for the five screening programmes. For the cancer programmes, these are reported in terms of performance against S7A requirements:

Screening Programme	Eligible population (millions)	Number invited 2017/18 (millions)	Number screened 2017/18 (millions)	Uptake (%)
Abdominal Aortic Aneurysm	0.29	0.28	0.23	80.5
Bowel (gFOBT)	8.7	4.4	2.5	57.7
Breast	7.2	2.51	1.8	71.1
Cervical	14.9	4.46	3.18	71.4
Diabetic Eye	3.3	2.7	2.3	82.7

Note: Only part of the eligible population will receive an invite each year (e.g. eligible women receive an invite every 3 years for breast cancer screening).

Screening Programme	Coverage (%)	Lower Threshold (%)	Agreed Standard (%)	Direction of change since 2016/17
Abdominal Aortic Aneurysm	77.6**	75	85	Static
Bowel (gFOBT)	59.6	55	60	Increasing
Breast	72.1	70	80	Static
Cervical	71.1	75	80	Declining
Diabetic Eye	82.7	75	85	Static

Note: AAA coverage figure for initial screen only. Note initial screens make up over 98% of AAA screens per year.

AAA Screening^{63,64}

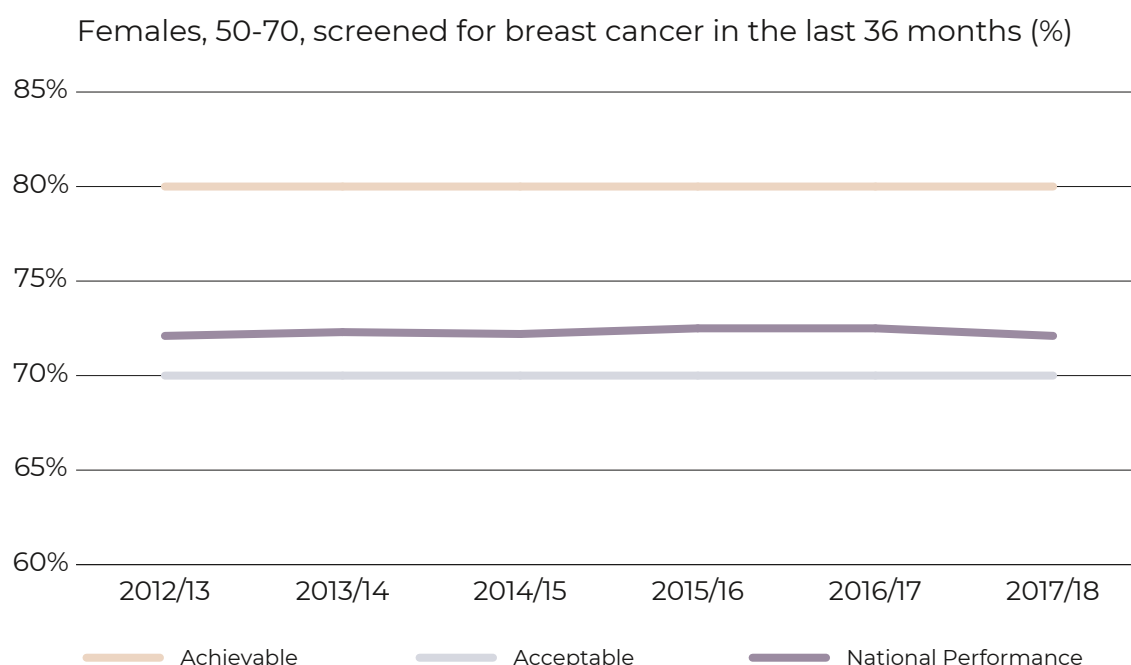
80.5% of eligible men were tested in 2017/18, which is above the acceptable standard of 74%.

Coverage was lowest in the most deprived decile (70.5%) and highest in the most affluent decile (87.6%). However, detection of aneurysms is highest in the most deprived populations. Coverage has increased from 2013/14 to 2017/18, although it slipped in London in 2017/18 during a recommissioning process.

Breast Screening⁶⁵

Breast screening met its lower threshold targets in 2017/18 for S7A but did not meet its standard target. In 2017/18, 71.1% of the eligible population were screened, which is above the acceptable level of 70%. Coverage was 72.1%.

The graph below illustrates how the proportion of women responding to an invitation to participate in the breast screening programme has remained static.



Bowel Screening⁶⁶

Bowel screening met its lower threshold targets in 2017/18 for S7A but did not meet its standard target. Performance against bowel screening standards is improving and is expected to improve further through implementation of the Faecal Immunochemical Test (FIT), but from a low starting point.

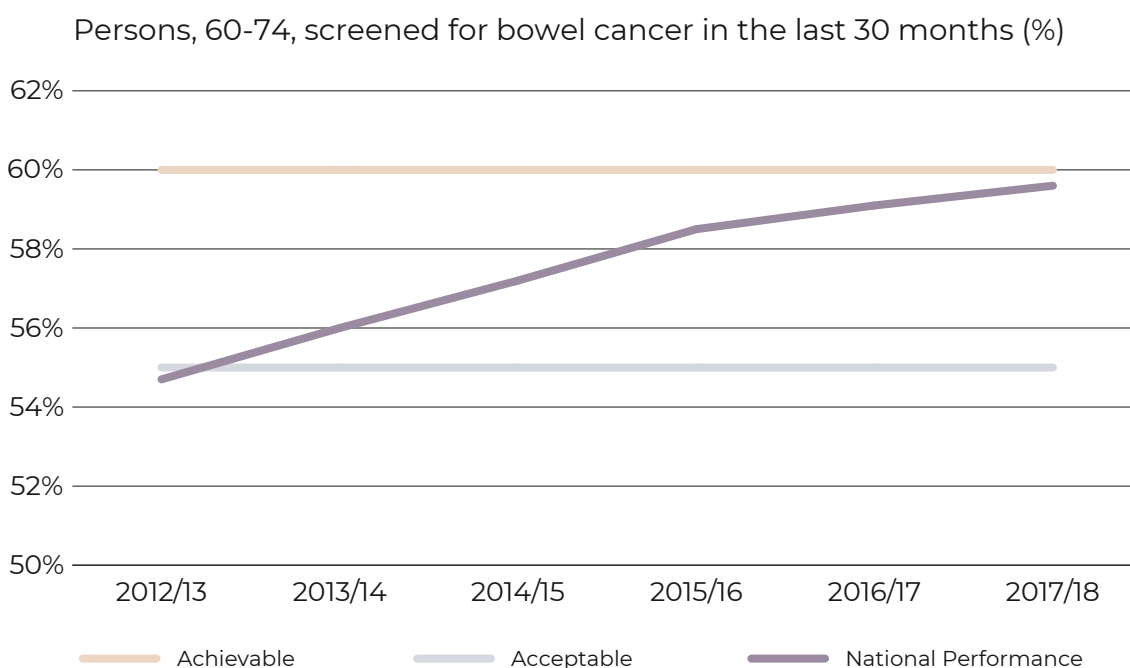
63 PHE annual report: Public Health England. 2018. NHS Screening Programmes in England. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/783537/NHS_Screening_Programmes_in_England_2017_to_2018_final.pdf. pp8

64 PHE KPI report: Public Health England. 2018. Screening KPI data summary factsheets - August 2018 - Issue 4. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/732590/Screening_KPI_SummaryFactsheets_August2018_Issue4.pdf. pp27

65 Public Health England. 2018. Public Health Profiles - Cancer Services.

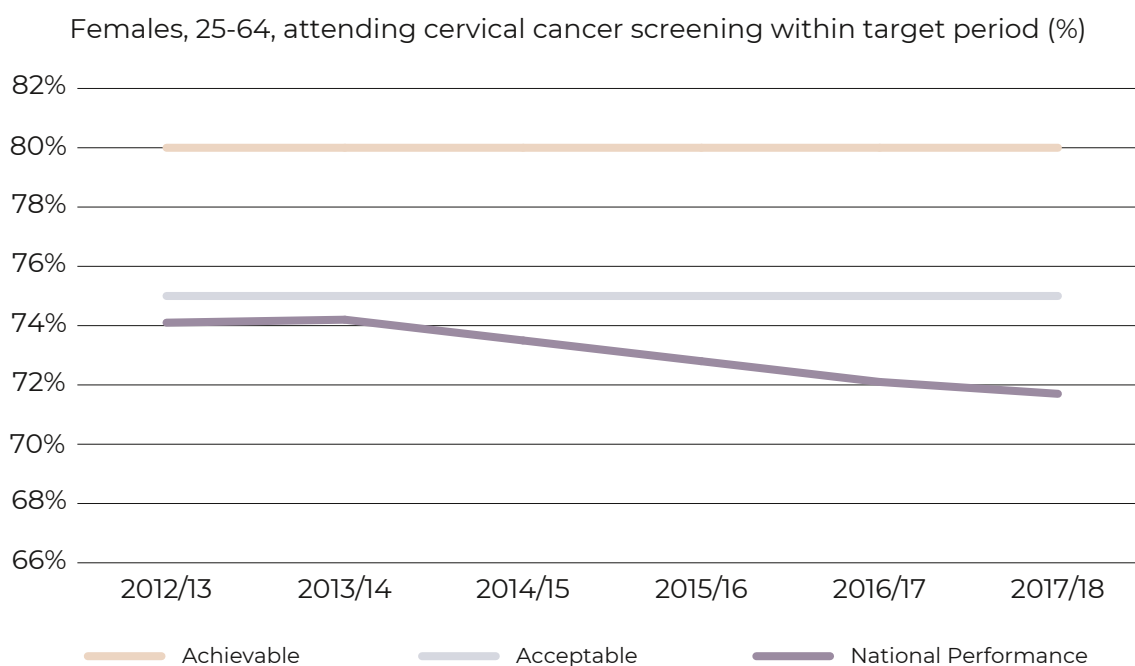
66 Ibid.

There are two elements to the current programme. Around 4.4 million people were invited for screening in 2017/2018, of whom 2.5 million people (57.7%) returned a sample. On bowel scope, around 337,500 were invited to testing in 2017/18, of which around 155,600 (46%) underwent a flexible sigmoidoscopy.



Cervical Screening⁶⁷

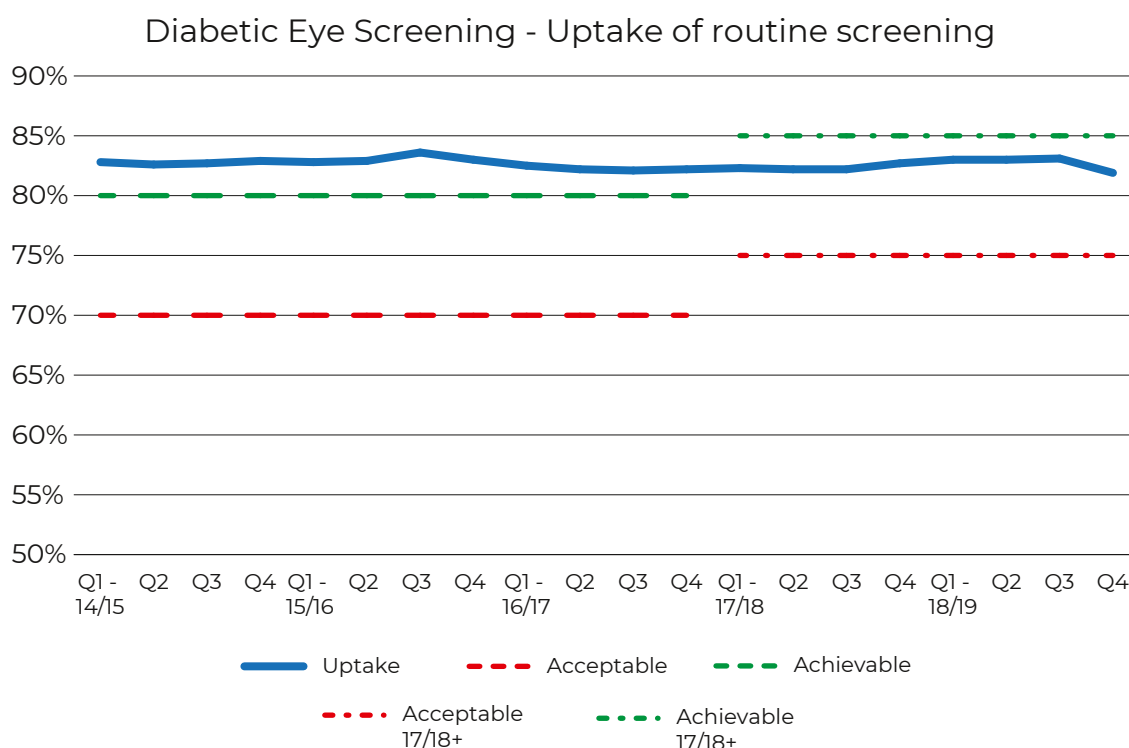
Cervical screening met neither its lower or standard threshold targets for S7A in 2017/18, which saw 71.4% of the eligible population screened against an acceptable level of 75%. The proportion of women responding to an invitation to participate in the cervical screening programmes has declined over time.



⁶⁷ NHS Digital, 2018. Cervical screening programme 2017-18.

Diabetic Eye Screening⁶⁸

Uptake of DES has remained broadly stable over the last four years and has consistently been above 80% since 2014.



HOW CAN UPTAKE AND COVERAGE BE IMPROVED?

Improving acceptability of the test

For most of the screening programmes, the acceptability of the test cannot immediately be improved. However, this is not the case for bowel screening. Large scale pilots have shown that the FIT test (involving the collection of a single stool sample only) has a significantly higher uptake than the Guaiac Faecal Occult Blood Test (gFOBT), which requires three samples. Uptake has increased by 8.5% since FIT was introduced in Scotland in November 2017, with the biggest improvement in participation seen amongst those living in the most deprived areas – up from 42.0% to 51.8%⁶⁹.

The changeover from gFOBT to FIT across England, which commenced in June 2019 is therefore very welcome but could have been introduced sooner. Since going live in June 2019, over 900,000 FIT kits have been issued. It is still too early to draw any conclusions as to the uptake of this new test though it is expected to increase by at least 7%.

68 Public Health England. 2019. Screening KPI data summary factsheets. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/824600/Screening_KPI_Summary_Factsheets_August-2019_Issue_8.pdf p61

69 ISD Scotland. 2019. Scottish Bowel Screening Programme Statistics. [ONLINE] Available at: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp#2347>. [Accessed 17 September 2019].

Acceptability of cervical screening may be improved by offering a self-sampling device to women who do not want the procedure done by a healthcare professional. Further testing will be needed in the UK before this can become a standard part of the programme, as set out in the case study below.

Case Study: HPV self-sampling

HPV self-sampling has been introduced in some countries including Australia, Netherlands and Hong Kong as a potentially more acceptable test for women who have not taken up standard cervical screening invitations. Results are encouraging, but further research is needed. This should be expedited.

The Netherlands, in 2016, was the first European country to move from a cytology-based to HPV-based cervical cancer screening, with cytology triage for those with a positive HPV test. Women who do not respond to their first GP request for testing are sent a self sample kit.

Australia has vaccinated for HPV since 2007 and is now moving to HPV DNA testing for all women, whether they have received HPV vaccination or not. A recent research paper of a randomised controlled trial published in 2016 has shown that home-based HPV self-sampling in Australia improves participation among never screened and under screened women⁷⁰. Most women with HPV detected then have appropriate clinical investigation.

IMPROVING AWARENESS

Several local initiatives have been undertaken to improve uptake through increasing levels of awareness of screening, each with encouraging success. These include a social media campaign to increase uptake of breast screening in Stoke on Trent, campaigns to increase uptake of cervical screening in Middlesbrough and Newcastle and a project involving telephoning non-participants in bowel screening in South West London.

At a national level, PHE ran a campaign to increase awareness and uptake of cervical screening earlier this year. This was relevant to all women, but was aimed particularly at younger women, South Asian and Black women, lesbian and bisexual women and women from lower socioeconomic groups. The campaign used several channels including TV, video on demand, washroom posters, media partnerships, social media and a partnership with 500 hair and beauty salons. During the months of the campaign, 86,000 more cervical samples were received by laboratories than in the comparable period in 2018.

70 International Journal of Cancer 2016 Jul 15;139(2):281-90 Home-based HPV self-sampling improves participation by never-screened and under-screened women: Results from a large randomized trial (iPap) in Australia. Available online: <https://www.ncbi.nlm.nih.gov/pubmed/26850941>

Case Study: Stoke on Trent – Social Media for Breast Screening⁷¹

A social media campaign in Stoke on Trent increased uptake of breast screening by more than 10%. North Midlands Breast Screening Service promoted their Facebook page on local community groups which their target group – women aged over 50 – regularly visited. This targeted approach empowered and enabled women to make appointments by reducing their anxiety around breast examinations. It also allowed them to communicate quickly and easily with health practitioners to ask questions about the screening process and make appointments.

Posts were designed to encourage women to share them and so spread the message about the benefits and importance of screening. Data on attendances for first time appointments at the North Midlands Breast Screening Service showed they increased by an average of 12.9% between three-year screening cycles from 2014 to 2018.

Case Study: ‘No Fear’ campaign for cervical cancer⁷²

In Middlesbrough, only two practices had reached the national cervical screening target of 80%, highlighting the need to carry out a town-wide campaign to target groups where uptake was low, such as women aged 25-34, Black, Asian and Minority Ethnic (BAME) communities and deprived communities.

The ‘No Fear’ campaign was launched in 2015 to minimise how daunting having a cervical screening test could be for some women. The campaign had practical tips for women such as booking a back to back “buddy appointment”, requesting a female nurse as well as allowing women to make online appointments, receiving text reminders and out of hours appointments. ‘No fear’ pharmacies were also developed, enabling women to seek advice and support relating to cervical screening. All ‘no fear’ practices saw an increase in cervical screening uptake, ranging from 0.6% to 6%.

71 PHE Screening - How the North Midlands Breast Screening team uses Facebook to increase breast screening uptake. [ONLINE] Available at: <https://phescreening.blog.gov.uk/2019/04/09/how-the-north-midlands-breast-screening-team-uses-facebook-to-increase-breast-screening-uptake/>. [Accessed 18 September 2019]. Page 63

72 Middlesbrough Council. 2019. No Fear. [ONLINE] Available at: <https://www.middlesbrough.gov.uk/social-care-and-wellbeing/public-health/screening-saves-lives/cervical-screening/no-fear>. [Accessed 24 September 2019].

Case Study: Community Links – South West London⁷³

In order to improve bowel cancer screening uptake in South West London, RMP Cancer Alliance procured Community Links, a local charity, to telephone patients who had received their gFOBT in the last six months but had not yet completed it. Evidence has shown that an intervention whereby patients are telephoned and provided with information about the screening test as well as being sent a GP endorsed letter can increase uptake by around 8%.

Community Links received a list of non-responders from GP practices across South West London and these patients were then contacted on up to three separate occasions at different times to increase the likelihood the patient could be reached. This included out of hours calls (evenings and weekends). Community Links worked closely with the London Bowel Screening Hub to send out replacement kits to patients who requested these and follow up calls were scheduled 4-6 weeks after the replacement kit had been ordered.

Over the duration of the project, Community Links spoke to nearly 13,000 patients, of whom 25% subsequently participated in bowel screening. An evaluation providing further detail is due to be made available to promote learning on how to improve participation in screening.

Although each of these initiatives appears to have been effective, they have generally not been subject to formal evaluation. This is a missed opportunity.

PROMOTING CONVENIENCE

There is substantial anecdotal evidence that people would be more likely to accept invitations to screening if appointments were available at convenient times and locations (either near home or a place of work). Indeed, researchers at University College London have shown that around half of non-attenders for cervical screening intended to be screened⁷⁴. These people are most likely to take up screening opportunities if screening could be made more convenient.

Some women also choose to be screened for cervical cancer through sexual health services. This is an important option especially as women tested through this route have an above average HPV positivity rate. Services in other locations (e.g. close to people's work) should be explored.

73 Hewitson P, Ward AM, Heneghan C, Halloran SP, Mant, D., 2011. Primary care endorsement letter and a patient leaflet to improve participation in colorectal cancer screening: results of a factorial randomised trial. *Br J Cancer*, [Online]. 105 (4), 475-480. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3170960/> [Accessed 17 September 2019].

74 Ryan M, Waller J, Marlow, L., 2019. Could changing invitation and booking processes help women translate their cervical screening intentions into action? A population-based survey of women's preferences in Great Britain. *BMJ open*, [Online]. 9:e028134. Available at: <https://bmjopen.bmj.com/content/9/7/e028134#ref-11> [Accessed 18 September 2019].

Barriers to improving convenience include poor IT systems, staff availability and funding to provide out of hours appointments. These are explored further in Chapter 10. However, some breast screening programmes, including those in London, do now offer out of hours or weekend appointments at some of their locations.

Case Study: ‘Computer Says No’ campaign⁷⁵

Jo’s Cervical Cancer Trust strongly advocates the provision of screening in settings that suit people going about their busy lives (e.g. closer to work). Their ‘Computer Says No’ report identified multiple barriers affecting access to cervical screening including lack of appointments, reduction of availability at sexual health services, IT systems preventing innovation, insufficient incentives and fragmented governance and commissioning in England. The report made a number of recommendations including that an integrated approach to commissioning and delivering screening must be taken across primary care and sexual health to ensure cervical screening is available in the settings which populations most require.

REMINDERS AND ENDORSEMENTS

Both GP endorsements and text reminders have been shown through RCTs to be effective in raising uptake. Although written endorsements by GPs supporting screening are now routinely sent out with screening information (e.g. in advance of a person receiving a bowel screening kit), the use of text reminders is variable. One of the challenges that screening providers have faced is accessing people’s mobile phone numbers to send a reminder before their first attendance. This is particularly important as attendances following a first invitation are particularly low.

Patients’ mobile phone numbers are now held by almost all GP surgeries. A London-wide project to obtain mobile phone numbers for people due for cervical screening (with consent from GPs) in order to send text reminders led to an increase in uptake of over 4%:

75 Jo’s Cervical Cancer Trust. 2018. Computer says “no”. [ONLINE] Available at: <https://www.jostrust.org.uk/our-research-and-policy-work/our-research/computer-says-no> [Accessed 18 September 2019].

Case Study: NHS London programme with iPLATO⁷⁶

Text message invitation reminders can help increase the number of women taking up the offer of cervical screening. NHS London invited GP practices to participate in a text message reminder project which launched in September 2018. iPLATO were commissioned to carry out the project and a steering group chaired by NHS London with representation from stakeholder organisations oversaw its implementation, and supported communication and GP engagement.

Five months into the project, 97% of practices in London had signed up and over 384,000 women had been invited for screening. Uptake of screening increased by 5.9% in women aged 50-64 and by 4.8% in women aged 25-49 for those who received a text reminder.

NHS London now plan to extend this to women due for breast screening. If this can be done in London, there is no logical reason why this should not be extended to the whole country and other screening programmes.

EQUITY OF ACCESS FOR UNDER-SERVED GROUPS

Screening has huge potential to help reduce health inequalities. As such, it is critical that active steps are taken to promote equity in access for under-served groups. People with physical disabilities, learning disabilities or mental health problems tend to have lower uptake of screening services than the general population. This may be because of difficulties with physical access to services, fear about what screening involves or low awareness of services.

As part of this review, a focus group was held with people who either did not speak English as their first language or had lower levels of literacy. It was striking that participants all reported they had received screening information or invitations in the post but none had heard about easy-to-read versions or those in their primary language. Whilst family members often helped to read the invitations and results, confusions easily arise. One participant commented for example that she found the invite very confusing and needed her husband to provide clarity. She didn't understand that screening was offered to everyone and therefore interpreted the invitation to mean that she might have cancer. Better and clearer communication is clearly key to improving uptake for this group.

This review has also heard of several local examples of effective actions that had been taken to improve uptake for people with learning disabilities. These include an initiative in Cornwall to promote uptake of breast screening for women with learning disabilities.

⁷⁶ Kerrison RS, Shukla H, Cunningham D, Oyeboode O, Friedman E, E., 2015. Text-message reminders increase uptake of routine breast screening appointments: a randomised controlled trial in a hard-to-reach population. *British Journal of Cancer*, [Online]. 10.1038, 1-6. Available at: <https://www.iplato.com/wp-content/uploads/2018/10/Breast-Cancer-Screening-Case-Study.pdf>

Case Study: Cornwall Learning Disability initiative for breast cancer⁷⁷

A programme led by screening liaison nurses in Cornwall increased screening uptake for people with learning disabilities beyond the level expected for the rest of the population.

As part of their breast screening awareness campaign, NHS England (South) created a short video to share their work in Cornwall which included tips on reasonable adjustments (changes to make things easier) which can make all the difference.

BLACK AND MINORITY ETHNIC GROUPS

Uptake of screening in some minority ethnic groups is significantly lower than in the rest of the population. Reasons for low participation include language barriers as described above, poor understanding of the screening process or its benefits, and other cultural barriers. A project in a GP practice in Whitechapel, East London, has shown how barriers to bowel screening can be overcome in a Bangladeshi population. Face to face discussions with non-participants, with a clear explanation of how to collect stool samples using gloves and collection dishes provided, led to uptake rates improving by 15% in less than a year. Joint working with faith leaders in a local community can also prove valuable.

A further study in Kirklees involved the Council and local health colleagues working with a local community centre (The Eden Foundation) to consider how to increase uptake in the Muslim community and understand the barriers which prevent or deter access to breast and cervical screening in particular. Permission on the grounds of religion was identified through focus groups as a key barrier to screening, and was not exclusive to the Muslim community. Working with Muslim scholars, the report suggested that education on the reasons for screening, along with arguments for both permissibility and impermissibility from a religious perspective may be presented to individuals to help facilitate an informed decision.

⁷⁷ NHS England - News. 2017. Campaign launched to help women with learning disabilities access breast cancer screening. [ONLINE] Available at: <https://www.england.nhs.uk/south/2017/10/02/learning-disabilities-breast-screening/>. Page 66

British Islamic Medical Association Cancer Screening Campaign⁷⁸

Building on earlier work with Cancer Research UK, a health promotion campaign aiming to promote cancer screening to the British Muslim community in their places of worship and congregation took place in 2019, lead by the British Islamic Muslim Association.

The campaign took place between February and March 2019, and involved 99 clinicians volunteering to present a standardised workshop in community centres and mosques. This was conducted in 43 settings and was complemented with a similar presentation on five popular community radio channels. 900 people attended the workshops and 166 feedback forms were collected for analysis. The majority of participants were women (66%) and from a diverse background, with 50% of Asian ethnicity. 26% of respondents were not aware of the national cancer screening programme before the talk, and 37% had not attended their scheduled cancer screening. Nearly all participants felt that their knowledge of cancer screening increased. After the workshop, more than 90% of respondents indicated that they would definitely attend their cancer screening and would recommend it to others. This compares to only 38% and 53% respectively before the workshop.

TRANS AND GENDER DIVERSE PEOPLE

Trans and gender diverse populations are currently poorly served by screening services. Transmen may have a cervix and thus be at risk of cervical cancer. However, their gender may be recorded as male and thus they would not be routinely called for cervical screening. Transwomen are at an increased risk of breast cancer compared to cisgender men if using hormones, but are only invited for screening if registered as female.

Clinicians and charities working in transgender healthcare strongly advocate that both sex assigned at birth, and gender, should be recorded on NHS records, so that people can be appropriately called for screening. This should be considered as part of the work on new IT for screening. In addition, staff involved in screening need to be educated about the specific needs of trans and gender diverse people in relation to screening.

⁷⁸ British Islamic Medical Association. 2019. Cancer screening awareness - importance and impact. [ONLINE] Available at: <https://www.britishima.org/?s=cancer>. p67.

RECOMMENDATIONS

This review recommends that:

- Recommendation 13:** High priority should be given to spreading the implementation of evidence-based initiatives to increase uptake. This will require an integrated system approach and should include:
- Implementing text reminders for all screening programmes
 - Further pilots of social media campaigns with formal evaluation and rollout if successful
 - Spreading good practice on physical and learning disabilities
 - Encouraging links with faith leaders and community groups and relevant voluntary, community and social enterprise organisations that work with the NHS at national, regional and local levels to reduce health inequalities and advance equality of opportunity
 - Increasing awareness of trans and gender diverse issues amongst screening health professionals
 - Consideration of financial incentives for providers to promote out of hours and weekend appointments.

8. WIDER PERFORMANCE ISSUES

Alongside uptake and coverage, other key performance indicators are vital in measuring the safety and quality of screening. Timeliness of sending results to patients following screening, and of arranging onward investigation and treatment as needed, are particularly important in this regard.

INTRODUCTION

As described in the previous chapter, uptake and coverage are the major determinants of the effectiveness of any screening programme. Other key performance indicators (KPIs) however are also vital in measuring the safety and quality of screening.

The data collected to monitor the cancer screening programmes is not routinely made publicly available. Information is shared with other NHS organisations for performance monitoring purposes but under strict data sharing terms which prohibit publication. This is in part due to legal requirements relating to the subsequent publication of Official Statistics by Public Health England and NHS Digital, which cannot be pre-empted. For example, this is the case for coverage and uptake statistics. The data in this chapter is therefore limited due to restrictions on publication of data.

The vast majority of people who undergo screening will have normal findings. It is nonetheless important for them to receive results without delay, so that they can be reassured. Where abnormalities are found, it is an important part of any screening programme that there is an appropriate follow-up investigation and treatment for those who require it, and that this is undertaken as soon as is reasonably possible.

It is beyond the scope of this report to consider every KPI across the five programmes. This chapter therefore considers those that are particularly likely to affect outcomes or patient experience as follows:

- Abdominal aortic aneurysm: Timeliness of results for all participants and timeliness of assessment by hospital services for those with significantly abnormal results.
- Bowel screening: Timeliness of results for all patients and time from abnormal test to assessment by a specialist screening practitioner, and then to a diagnostic test (e.g. colonoscopy). In addition, the adenoma detection rate at colonoscopy is a measure of quality of the procedures.

- Breast screening: Timeliness of results for all patients and timeliness of assessment for those with abnormal results and onwards referral for those found to have cancer. In addition, the interval between screening (roundlength) is important.
- Cervical screening: Timeliness of results for all patients and time to colposcopy for those with abnormal results.
- Diabetic Eye Screening (DES): Timeliness of results for all patients and timeliness of being seen at hospital eye services for those with proliferative retinopathy.

It is worth noting that some of these were also highlighted in the National Audit Office's (NAO) recent investigation⁷⁹ and subsequent Public Accounts Committee report⁸⁰.

ABDOMINAL AORTIC ANEURYSM SCREENING⁸¹

In 2017/18, 230,000 people were screened. Participants are told the results of their screen straight away during their screening attendance. The proportion of these people with an aortic diameter greater than 5.5 cm who were seen by a vascular specialist within two weeks was 94.3%.

BOWEL SCREENING⁸²

In 2017/18, 100% of the bowel screening (gFOBT) test kits sent by participants were reported within two weeks of being received by the reporting laboratory. For those with positive results, 98.8% were offered a fitness assessment with a specialist screening practitioner within the required two weeks of their referral date. The time from that initial assessment to a diagnostic test (usually colonoscopy) should be less than 14 days from this assessment. Approximately 82.9% of patients were offered a diagnostic test in that time.

An important measure of quality of colonoscopy is the adenoma detection rate. This is the proportion of all patients undergoing colonoscopy who have at least one histologically confirmed adenoma. At a national level, the detection rate was 52.4%, but varied between colonoscopy centres from 43.7% to 67.1%.

BREAST SCREENING⁸³

In 2017/18, 95.5% of patients who underwent screening mammography received their results within two weeks. For those with abnormal findings at mammography, 91.2% were offered an attendance within three weeks against an acceptable standard of 98%.

79 National Audit Office. 2019. Investigation into the management of health screening.

80 UK Parliament. 2019. Public Accounts Committee - Adult Health Screening Inquiry.

81 Public Health England. 2018. PHE Screening - AAA screening annual data for 2017 to 2018.

82 Public Health England. 2018. Public Health Profiles - Cancer Services.

83 Ibid.

In some cases, a screening mammogram can result in potentially abnormal findings. For the women affected, the period until they are assessed and cancer is either diagnosed or ruled out can be associated with high levels of anxiety. Keeping this interval to a minimum is therefore of great importance.

Breast Screening Roundlength

Breast screening roundlength refers to the interval between screens, which should be less than 36 months. In 2017/18, 8% of women waited more than 36 months between breast screening appointments⁸⁴. If women are made to wait longer than 36 months between screens, the risk of cancers developing and presenting symptomatically increase. These cancers may be incurable.

The National Audit Office also noted variation across the country in their report, highlighting that in 2017/18, 22 out of 79 providers did not meet the lower threshold target of inviting at least 90% of eligible women for a screening appointment within 36 months of their previous appointment⁸⁵.

Good practice suggests services should aim for a 34-month roundlength in the context of the overarching 36-month roundlength target, thereby providing a buffering period and helping to avoid breaches. System capacity is also a key issue here and is considered further in Chapter 10.

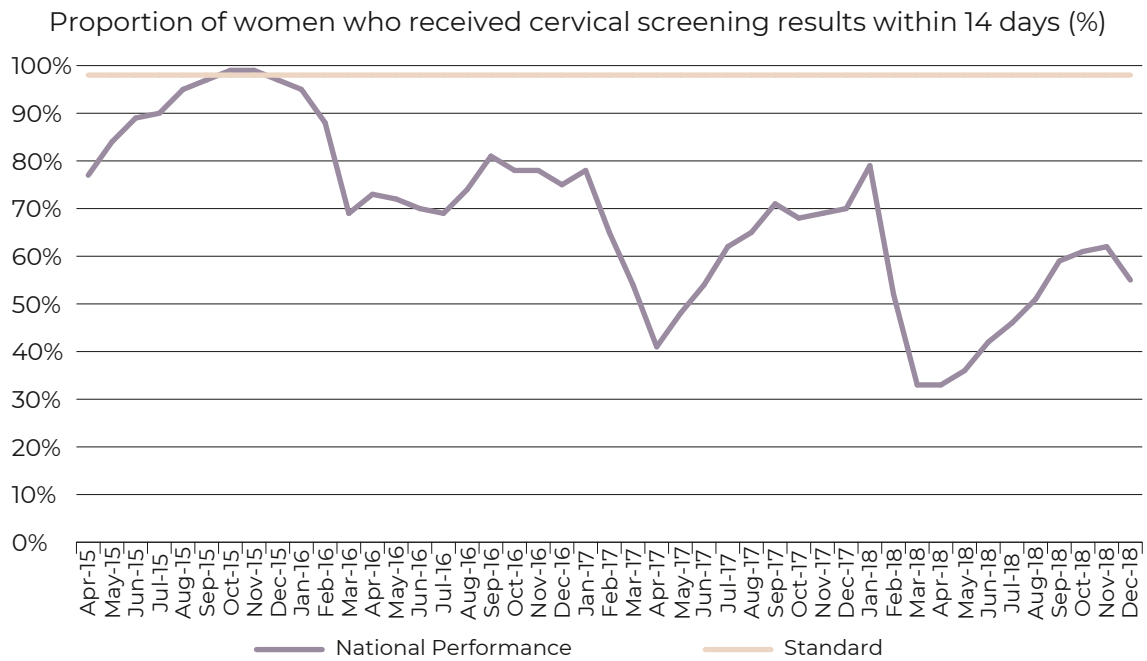
CERVICAL CANCER SCREENING⁸⁶

One of the key standards within the cervical screening programme is that at least 98% of women should receive their test result within two weeks of the sample being taken. This is known as the 14-day Turnaround Time (TAT) performance standard and was set in 2010. The standard was last achieved in October 2015 and in February 2019, only 46% of women received their cervical screening results within 14 days.

84 Parliament.uk. 2019. Adult health screening. [ONLINE] Available at: <https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/1746/174606.htm>

85 National Audit Office, 2019. Investigation into the management of health screening. pp7-9.

86 NHS Digital, 2018. Cervical screening programme 2017-18. [ONLINE] Available at: <https://files.digital.nhs.uk/B1/66FF72/nhs-cerv-scre-prog-eng-2017-18-report.pdf>.



Performance has been falling in recent years with sharp declines in the early months of each calendar year. These may be due to GPs undertaking more cervical samples in that time to achieve payment under the Quality and Outcomes Framework, but may also be influenced by awareness campaigns at that time of year. The overall decline has resulted from the changeover from liquid-based cytology as the primary screening test to primary HPV testing. As this new approach to screening is being done in fewer laboratories, cytologists have voted with their feet in anticipation of the change, putting remaining services under the strain. Ultimately, when the transition has been completed the performance on turnaround times should revert to their pre-2015 levels, but this will need to be very closely monitored.

Time from cervical screen to colposcopy

Women who have abnormal results may be referred to hospital for a colposcopy. The standard is that no more than 1% of patients should wait longer than six weeks from the point of referral.

In 2017/18, 99.5% of women with high grade abnormalities (high-grade dyskaryosis -moderate or severe) on screening were offered an appointment within four weeks from referral to first offered appointment. For all people requiring colposcopy, 40.6% were offered an appointment within 2 weeks and 98.5% within 8 weeks.

DIABETIC EYE SCREENING⁸⁷

One of the key performance indicators for DES is that participants should receive their results within three weeks. In 2017/18, this was achieved in over 94% of cases.

People with diabetes who are found to have proliferative retinopathy should be seen by a hospital eye service within six weeks. In 2017/18, this was achieved in 75.8% of cases against an acceptable standard of 80%. The overall standard has not been met for three years. Only 34 of 62 providers in 2017/18 met the acceptable standard, highlighting the need for close collaboration between DES and hospital eye services.

RECOMMENDATIONS

This review recommends that:

- Recommendation 14:** Breast screening providers should aim to invite people at 34-month intervals after their previous appointment so that all participants can be screened within 36 months and therefore avoid slippage.
- Recommendation 15:** Across all screening programmes, getting the results of screening to patients within the standard timeframes should be achieved. This is particularly important for cervical screening where performance has fallen markedly.
- Recommendation 16:** Time to assessment and where necessary, further treatment, should be closely monitored across all programmes and publicly reported as part of faster diagnosis standards.

⁸⁷ Public Health England. 2018. Annual 2017-18 Publication YPA KPI data. [ONLINE] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/769453/Annual_2017-18_Publication_YPA_KPI_data_V1_NE.ods

9. FINANCIAL INCENTIVES TO IMPROVE OUTCOMES AND UPTAKE OF SCREENING

Many screening programmes are currently provided through block contracts, which provide little incentive to providers to actively improve uptake. In addition to the recommendations made in Chapter 7, financial incentives – such as moving to payment by tariff or enhancements to GP payment systems (either at practice or primary care network level) – could further increase uptake of screening and improve the quality of screening services. This chapter does not consider financial incentives to encourage the public to participate in screening.

INTRODUCTION

There is currently no national approach to tariffs in the screening programmes, with the application of a standard national tariff not currently permissible in this context without legislation. Most services are on block contracts where providers are paid a fixed sum based on the population served. Non-mandatory tariffs could be developed. Some contracts are based on local cost per case arrangements but this is not widespread. There is therefore limited incentive for the provider to improve uptake.

This chapter considers the potential of further financial incentives to improve uptake across the screening programmes where this has been identified as an issue, namely the screening programmes for:

- Bowel cancer
- Breast cancer
- Cervical cancer.

Role of financial incentives

There is some evidence that financial incentives can work in a screening context. In cervical screening for example, there are seasonal peaks in turnaround time which are thought to reflect increased activity as general practices seek to achieve their Quality and Outcomes Framework target.

Before introducing any further financial incentive however, it is important to carefully consider which aspects of screening performance would be enhanced and which level of service provider should be targeted (e.g. GP practice,

screening hub, imaging or endoscopy service provider or laboratory). These considerations will be different for each screening programme and will be greatly facilitated once new IT systems are in place.

Where they are to be used, any tariff for screening should also be fair and recognise the complexity of the screening process. For example, a tariff for screening colonoscopy should be higher than that for symptomatic colonoscopy, as patients identified through screening undergo assessment by a specialist screening practitioner. At colonoscopy, the proportion with polyps requiring removal is also higher than that for symptomatic patients, taking more time during the procedure and creating more work for pathology departments.

BOWEL SCREENING

Although the introduction of the Faecal Immunochemical Test is expected to increase uptake from around 60% to a likely level of around 67% or 68%, the aspiration is to achieve around 75% nationally. Financial incentives for GPs, screening hubs and colonoscopy service providers should all be considered.

Incentives for GPs

Other than through the standard endorsements on invitation letters, GPs are not currently incentivised to encourage participation in bowel screening. Indeed, some GPs have reported to this review that they feel less involved in the bowel screening programme than in either the breast or cervical screening programmes. This is despite the evidence base for the effectiveness of bowel screening in reducing bowel cancer mortality being widely accepted. Financial incentives to encourage GPs to promote uptake in people who have not participated within a set time of being sent a kit should be considered, taking into account of course, the need to minimise the administrative burden on general practice.

Incentives for screening hubs

Screening hubs send kits to eligible members of the public, answer queries through helplines, analyse the kits when received back, inform participants of the results, ensure onward referral to colonoscopy centres and inform GP practices about non-participants. Abandoned call rates are already measured by hubs as if a telephone helpline is not answered swiftly, some people may be put off participating. A targeted payment for an enhanced service approach (e.g. a CQUIN) could be introduced to encourage low abandoned call rates.

Incentivising colonoscopy centres

Most screening colonoscopy centres are currently paid through a block contract. Although all such screening centres will provide colonoscopy for all appropriate patients, there is little or no incentive for them to prepare for planned changes in the age range and sensitivity levels of the bowel screening programme. As set out in Chapter 10, it is anticipated that symptomatic colonoscopy (for which there is a tariff) will reduce significantly over coming

years whilst screening colonoscopy capacity will need to increase markedly. Endoscopists currently only undertaking symptomatic colonoscopies will need additional training to undertake the more complex screening colonoscopies. A tariff for screening colonoscopies might incentivise this.

BREAST SCREENING

The need to increase uptake and offer greater convenience to patients has been discussed in earlier chapters. Block contracts are currently used. Uptake could be incentivised by moving to a tariff approach for providers of mammography services. Alternatively, targeted payments at enhanced services could similarly be used based on a percentage improvement in uptake. These could usefully be targeted at low uptake areas and the additional funding used to staff out of hours services and to send text reminders.

CERVICAL SCREENING

The large majority of cervical samples are undertaken in primary care. However, samplers may not be available at times that suit patients. While this may be difficult to resolve at an individual practice level, particularly for small practices, the introduction of primary care networks provides a new opportunity to provide more convenient services within a reasonable distance of people's homes. Primary care should be incentivised to provide screening services at times which are convenient for people who are eligible for screening.

Whilst primary care is the main provider of cervical screening, some women may choose to undergo cervical sampling close to their place of work, rather than close to home, or through sexual health services as set out in Chapter 7. Consideration should therefore also be given as to how best to incentivise alternative providers.

RECOMMENDATION

This review recommends that:

Recommendation 17: NHSE should urgently consider how best to use financial incentives to increase uptake of cancer screening services and to encourage providers to prepare for the future, especially with regard to bowel screening.

10. CREATING CAPACITY FOR CHANGE

Screening programmes are currently constrained by the size and nature of their workforce, and the equipment and facilities available to them, which will act as a barrier to implementing the recommendations set out in this report unless immediately addressed. Creating capacity for this to change is key to ensuring screening programmes that are fit for the future.

WORKFORCE

The screening workforce is dedicated but is being put under increasing strain as eligible populations for screening increase. This has been significant in recent years, partly due to the ‘baby boom’ generation now being in the age range for breast and bowel screening. Each of the adult screening programmes additionally face their own specific workforce challenges and without adequate planning, the recommendations made through this review could put further pressure on the workforce (through the drive to increase uptake by offering more convenience to patients, for example).

The introduction of artificial intelligence is expected to reduce workload and minimise pressure on the workforce at a future point (see Chapter 2). However, these are no panacea and workforce implications need to be fully understood and considered prior to implementation. Indeed, the Royal College of GPs set out a clear warning of the unintended consequences of genetic screening on the workload of an already strained primary care earlier this year⁸⁸.

ABDOMINAL AORTIC ANEURYSM

Screening for abdominal aortic aneurysm (AAA) is a relatively small programme and is generally performing well. The close linkage between the AAA screening programme and vascular surgical services is a key strength.

BOWEL SCREENING

Bowel cancer screening is resource intensive, particularly within endoscopy and pathology and there is a need for a highly trained workforce and specialist facilities. The main challenge for bowel screening is to lower the starting age from 60 to 50 years, and to increase the sensitivity threshold of the Faecal Immunochemical Test (FIT) as quickly as possible, in line with recommendations

88 Royal College of General Practitioners. 2019. Genetic testing should never be taken lightly, says RCGP. [ONLINE] Available at: <https://www.rcgp.org.uk/about-us/news/2019/march/genetic-testing-should-never-be-taken-lightly-says-rcgp.aspx>

of the UK National Screening Committee (UK NSC). While the five screening hubs have the capacity to process more FIT tests, optimising bowel cancer screening will have inevitable consequences for the workforce.

Case Study: Optimising the FIT threshold and age-range for bowel screening

A recommendation was made by the UK NSC in 2015 to modify the bowel cancer screening programme by replacing the Guaiac Faecal Occult Blood Test (gFOBT) with FIT. FIT is a quantitative test that measures the amount of human blood in a stool sample via specific antibody binding to human haemoglobin. NHS England began the roll-out of FIT testing from June 2019.

In the quantitative FIT test, a threshold is set whereby samples containing over a certain amount of blood will require further follow-up tests. A lower threshold will result in a greater number of referrals and thereby detect more cancers. The UK NSC made a further recommendation in 2018 that FIT testing should be offered to people aged 50-74 at as low a threshold as possible, nearing 20µg/g.

FIT will be initially offered to people living in England aged 60-74 with the test running at a threshold of 120µg/g and it is anticipated that the age range and FIT threshold will, over time, be adjusted to meet the UK NSC recommendations. In January 2019, the NHS Long Term Plan committed to lowering the starting age for bowel screening to 50⁸⁹.

Colonoscopy capacity

Demand for screening colonoscopy is set to increase during 2019/20 as a result of the switch from gFOBT to FIT. This is partly due to the anticipated increase in uptake. As FIT is also more sensitive than gFOBT, more positive results are expected, leading to more people being referred for colonoscopy.

Around 700,000 colonoscopies are currently undertaken in England each year. These can be categorised as resulting from screening activity, symptomatic presentation or for surveillance purposes. Major changes in the numbers of colonoscopies required in each of these groupings is anticipated over the coming years, which impacts planning at both national and local level:

- **Screening** Screening colonoscopies take 1.5 times as long as one done for symptomatic causes, largely because of the higher pick up rate of polyps and adenomas. Screening colonoscopies also require an additional skillset. Around 50,000 colonoscopies are currently performed every year on people who test positive on gFOBT/FIT, and on a relatively small number of people found to have significant abnormalities through bowel scope screening. As set out in Chapter 4, the starting age for bowel screening is to be lowered from age 60 to 50, and the sensitivity threshold for FIT is to be increased. It is

89 NHS England. 2019. The NHS Long Term Plan.

anticipated that this will lead to a major increase in the number of screening colonoscopies required every year. This will be considered further in the subsequent planned report on diagnostic capacity (see Chapter 3).

- **Symptomatic** A further 550,000 colonoscopies are performed annually on patients who are referred to hospital services by their GPs – often through an urgent referral pathway with lower gastrointestinal symptoms – together with some patients who present to hospitals as emergencies. It is hoped that the introduction of highly sensitive FIT testing in primary care for patients who present with gastrointestinal symptoms will separately lead to a marked reduction in urgent referrals to hospital services and thus a further drop in demand for symptomatic colonoscopies. Early results of trials of FIT testing in primary care are encouraging, but further follow up is required to ensure the safety and impact of this approach.
- **Surveillance** Around 100,000 colonoscopies are performed every year on patients who have undergone a previous colonoscopy and been found to have polyps, for which a follow up colonoscopy has been recommended. This includes both those following screening and those following symptomatic colonoscopy. The British Society for Gastroenterology and PHE are due to publish new guidelines on indications for surveillance colonoscopy which are expected to recommend a very substantial reduction in surveillance colonoscopy. The guidelines are likely to be welcomed by gastroenterologists and should free up capacity in endoscopy services over the next 1-2 years if systematically implemented.

These changes result in major shifts in the indications for colonoscopies, but not necessarily an overall increase in demand. Since we know that lowering the age and threshold for FIT testing will improve the effectiveness of the programme – and save more lives – the system must urgently consider and plan for this. The full impact on diagnostic and symptomatic services must be understood to enable screening hubs and centres to prepare for full implementation, building on activity already being taken forward by Health Education England (HEE). Colonoscopy activity will need to be very closely managed over the next few years.

BREAST SCREENING

The expanding eligible population was set out in Chapter 7. With symptomatic breast services experiencing a similar increase in workload to screening services, both find themselves in competition for the same services.

Capacity is placed under further strain by the fact that considerable proportions of the radiologist and radiographer workforce are now approaching retirement. If proposals to increase uptake – particularly through out of hours and weekend provision of appointments – and maintain 36-month roundlength are implemented, this will result in even further pressure on this diminishing workforce.

New workforce models for breast screening were implemented around 15 years ago, in response to the plan to extend the upper age of screening from 65 to 70. This was the first example of the four-tier model (assistant practitioner; registered practitioner; advanced practitioner and consultant practitioner) within the NHS. Working with HEE, the Royal College of Radiologists, and the Society and College of Radiographers, the breast screening programme now needs to go further, with a strong focus on training and retaining the workforce of the future.

HEE is already working with the screening programme and with the relevant professional bodies to introduce new workforce models including the training of associate mammographers. The role of the assistant practitioner needs to be extended so that they can work autonomously on mobile vans. More radiographers may also need to be trained to report mammograms in areas where there are shortages.

As already outlined in Chapter 4, artificial intelligence (AI) will also be key to relieving pressures going forwards and AI algorithms for reading mammograms are now at an advanced stage of development. Whilst it is envisaged that AI will eventually replace one of the two human readers, these need to be formally tested as soon as possible to ensure they are at least as accurate as a trained human reader.

Case study: Potential AI Evaluation System

An AI mammogram evaluation system to support the commissioning of mammogram reading could help address the workforce crisis in breast cancer screening. Developing a safe, effective and robust AI solution to replace one of the two current readers will free up workforce time for half of these scan reads. Prior to entry into the NHS supply chain, each provider's AI needs to be evaluated against a standard to ensure that it is safe and effective for use in the Breast Cancer Screening Programme. The AI Investment Fund would support the robust development of this AI evaluation, to ensure that only accurate, consistent tools are commissioned which NHS can use with confidence.

Cervical screening

The change from primary cytology to primary HPV testing for cervical screening is very welcome and will improve outcomes for patients. The transition has however led to major changes in workforce requirements in laboratories, with the number of providers delivering cervical screening to reduce from 46 to eight. The immediate impact of this on service delivery, and the workforce itself, was unfortunately not sufficiently considered and mitigated against.

The new technology used by primary HPV testing reduces the number of samples requiring assessment under a microscope by around 85%. Fewer cytoscreeners - who perform this activity - are therefore required. Recognising

this, many have left to seek alternative work, leaving providers experiencing difficulty in retaining and recruiting staff to continue the existing cytology screening service. This has resulted in breaches of the 14-day turnaround time standard as explored in Chapter 7, and the culmination of a backlog of samples waiting to be read in laboratories.

A number of initiatives have been introduced across the country to reduce these backlogs, including laboratories offering overtime for staff, pilot sites being used to create additional capacity for struggling laboratories, and allowing the conversion of existing service providers to HPV primary screening ahead of the completion of the mobilisation and consolidation process. It is as yet unclear however, whether the eight laboratories that will be providing the new service and will become responsible for ensuring appropriate staffing, will be able to do this within the timeframes agreed.

The requirement that all samples should be assessed on one of the eight sites may (at least in the short term) therefore need to be revisited. HEE and NHS England (NHSE) should also work together to ensure that cytoscreeners who are no longer required are urgently redeployed elsewhere in pathology services (e.g. in assessing bowel polyps). Networks can proactively work with staff impacted by this change and assess where they present an opportunity to develop new and equivalent roles.

Diabetic eye screening

The marked year-on-year increase in the number of people with diabetes is putting a considerable strain on diabetic eye screening services. Impact on the screening workforce can be mitigated in the short to medium term by increasing the screening interval from one to two years for people at low risk. This has already been agreed in principle but needs to be implemented as soon as is safely practicable. It would be greatly facilitated by the introduction of a single new IT system.

EQUIPMENT AND FACILITIES

Equipment and facilities for screening have not kept pace with demand. Several providers which are hosted by NHS trusts reported to the review team that the replacement of screening equipment - including both mammography machines and mobile vans - is not considered affordable given wider demands on capital budgets. The replacement of capital equipment is a particular issue for trusts given severe constraints on capital funding and huge demands for other capital investment, such as backlog maintenance.

This is a particular issue for breast screening. Some mobile vans for breast screening are at least 17 years old and have leaking roofs. In some Trusts, equipment and facilities are used both for screening and for symptomatic patients. This puts further pressure on service providers in the context of year-on-year increases in the number of referrals of women with breast symptoms. Last year, saw a 20% increase in the number of women with breast symptoms being referred to hospital services in England.

The Prime Minister's recent announcement⁹⁰ of £200 million new funding to replace MRI machines, CT scanners and breast screening equipment is a welcome first step in addressing this issue.

PROVIDER LANDSCAPE

Some of the 78 breast screening services are small and may be unsustainable in the long term. While this has been raised in the course of this review, a formal assessment has not been undertaken.

The review has however already set out a recommendation in Chapter 5 that local screening services work more closely with comparable services for patients presenting symptomatically (e.g. mammography, endoscopy and colposcopy). Commissioners should also work closely with cancer alliances and emerging primary care networks to ensure close join-up at local level, particularly where planned implementation of screening will impact on related service delivery. The expected temporary increase in the number of colposcopies needed as a result of the move to primary HPV testing is a prime example of this.

RECOMMENDATIONS

This review recommends that:

- Recommendation 18:** National guidance should be provided to allow local commissioners and providers to plan for the required changes in colonoscopy and any future screening programme changes. Commissioners of screening and symptomatic services will need to work together on this. Cancer Alliances can facilitate this working in collaboration with the NHSE public health commissioning teams.
- Recommendation 19:** Training of screening colonoscopists should be given very high priority by HEE. Providing endoscopists who are already undertaking symptomatic colonoscopies with additional skills should be encouraged.
- Recommendation 20:** A dedicated capital fund or similar approach to support the purchasing of screening equipment and facilities should be established to replace old equipment and meet future activity increases, given the competing priorities for capital allocation in the system.

90 Government News, 2019. Prime Minister pledges funding for cancer screening overhaul. [ONLINE] Available at: <https://www.gov.uk/government/news/prime-minister-pledges-funding-for-cancer-screening-overhaul>

11. IMPROVING AUDIT AND RESEARCH

Research is clearly essential if any new screening programmes are to be introduced. In addition, both audit and research are necessary to ensure that existing programmes are achieving what they set out to do and are improved wherever possible.

INTRODUCTION

Existing NHS screening programmes provide a unique platform to evaluate the effectiveness of screening interventions. This is enhanced by the size of the populations served and the standardised way in which the programmes are delivered. Despite having the expertise, logistics and financial opportunities to pursue such research, our engagement with researchers has identified that many barriers still exist, resulting in frustration and significant delays to research.

This chapter looks at:

- Audit and monitoring
- Research into current screening programmes
- Research to support new programmes
- Looking beyond screening
- Barriers to progress

AUDIT AND MONITORING

Research into existing screening programmes is heavily dependent on the collection and availability of good quality data. This data is essential to monitoring the performance of each programme and being able to measure the impact of interventions against expected performance. However, data availability, quality and publishing frequency cause frustrating difficulties in assessing how the system is performing in real-time.

NHS Digital do publish annual reports on breast and cervical screening, which meet the criteria set by the Office of National Statistics. However, this is still not the case for bowel screening, despite the programme having been up and running for well over a decade. National statistics for bowel screening are however published for the NHS in Scotland.

RESEARCH INTO CURRENT SCREENING PROGRAMMES

Important research has been undertaken in this country to assess factors underlying poor uptake of screening⁹¹ and interventions which can help to increase uptake. These include randomised controlled trials (RCT) to evaluate the impact of GP endorsements⁹² and text reminders⁹³ which underpin some of the recommendations in Chapter 7. Equally important is research that investigates whether additions or modifications to existing programmes could increase benefits. Researching interventions to optimise performance and modify the screening programmes is equally important and should be supported:

Case Study: The Age Extension (AgeX)

AgeX is assessing the impact of extending the age range for breast screening to include women aged 47-49, and 71-73. No other country could undertake a RCT of the magnitude of AgeX, which is needed to yield definitive results on the benefits and harms of screening in these age groups. Already over 4 million women have been entered into this trial, making it the largest RCT for any condition anywhere in the world. It is being funded by Cancer Research UK, Public Health England, Department of Health and Social Care and the Medical Research Council. The Independent Review of Breast Screening gave a clear recommendation that this trial should continue⁹⁴.

Case Study: Endocuff Vision®

This is a device which attaches to the colonoscope and improves visualisation of the bowel. The Accuracy of Detection using Endocuff Optimisation of Mucosal Abnormalities (ADENOMA) RCT found it led to an increased adenoma detection rate among the positive guaiac faecal occult blood test screening population. Integration with the bowel screening programme was essential in proving these benefits and Endocuff Vision has been fast-tracked through the NHS Innovation and Technology Payment programme⁹⁵. It is an excellent example of additions and modifications to screening to improve earlier detection of cancer and save more lives⁹⁶.

91 Marlow et al., 2017 – Understanding the heterogeneity of cervical cancer screening non-participants: Data from a national sample of British women <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5489076/>

92 Christian von Wagner et al. – Use of a GP-endorsed 12 months' reminder letter to promote uptake of bowel scope screening: protocol for a randomised controlled trial in a hard-to-reach population <https://bmjopen.bmj.com/content/8/5/e022263>

93 Kerrison RS, Shukla H, Cunningham D, Oyebo O, Friedman E, E., 2015. Text-message reminders increase uptake of routine breast screening appointments: a randomised controlled trial in a hard-to-reach population.

94 Thomas, L, Gore, M, Wyman, P. The Independent Breast Screening Review 2018. pX

95 The AHSN Network. 2019. Endocuff Vision® – ITP. [ONLINE] Available at: <https://www.ahsnnetwork.com/supporting-innovation/innovation-technology-payment-itp/innovation-and-technology-payment-itp-2018-19/endocuff-vision-itp-product-information>.

96 Ngu WS, Bevan R, Tsiamoulos, Z., 2019. Improved adenoma detection with Endocuff Vision: the ADENOMA randomised controlled trial. Gut, [Online]. 68, 280-288. Available at: <https://gut.bmj.com/content/gutjnl/68/2/280.full.pdf>

Research to support new programmes

New screening programmes are only implemented when there is sufficient evidence that the benefits outweigh the harms and that the programme will be cost-effective. There are many diseases for which late-stage diagnosis is still a fundamental problem and it is crucial that researchers identify whether screening (be it at a population or more targeted level) would be a beneficial and cost-effective intervention for other diseases.

Looking beyond screening

The NHS in England provides a valuable platform for research that is second to none and efforts should be made to utilise this opportunity for research both inside and outside of the screening programmes. The national screening programmes have to date provided very good platforms for research beyond screening itself. Notable examples include:

Case Study: Million Women Study⁹⁷

The Million Women Study recruited participants between 1996 and 2001 and was undertaken as an adjunct to the breast screening programme. It is a valuable study looking at the links between lifestyle factors and disease-risk in a very large cohort (over one million women!). It has provided key findings including evidence on the long-term reduction in risk of endometrial cancer from use of oral contraceptives⁹⁸ and evidence on lung cancer in never smokers⁹⁹.

Case Study: Gut Biome¹⁰⁰

More recently, samples from the NHS bowel screening programme are being used to address important questions about the gut microbiome and associations with bowel cancer. Researchers are profiling the bacterial content in stool samples to identify whether analysis of an individual's microbiome could improve the performance of existing screening tests. Research currently looks promising and has identified a group of bacteria associated with bowel cancer. However, it is vital that validation is thorough, and work is therefore ongoing. This work is currently being funded as part of Cancer Research UK's Grand Challenge awards and samples are provided from the Bowel Cancer Screening Southern Programme Hub.

97 Beral, V et al. (1996-2001) University of Oxford. 2019. The Million Women Study. [ONLINE] Available at: <http://www.millionwomenstudy.org/introduction/>

98 Collaborative Group on Epidemiological Studies on Endometrial, C., 2015. Endometrial cancer and oral contraceptives: an individual participant meta-analysis of 27276 women with endometrial cancer from 36 epidemiological studies. *Lancet Oncology*, [Online]. 16, 1061-70. Available at: <https://www.thelancet.com/action/showPdf?pii=S1470-2045%2815%2900212-0>.

99 Pirie K, Peto R, Green J, Reeves GK, Beral V; Million Women Study Collaborators. Lung cancer in never smokers in the UK Million Women Study. *Int J Cancer*. 2016;139(2):347-354. doi:10.1002/ijc.30084.

100 Cancer Research UK. 2019. Manipulating the microbiome to beat bowel cancer. [ONLINE] Available at: <https://www.cancerresearchuk.org/funding-for-researchers/how-we-deliver-research/grand-challenge-award/Manipulating-the-microbiome-to-beat-bowel-cancer>.

BARRIERS TO RESEARCH

Throughout this review, researchers have highlighted major concerns about the barriers they face in undertaking research into screening. These barriers are probably not unique to screening but are amplified by the large number of organisations involved and the number of different datasets that may need to be combined to undertake some types of screening research.

Data controllers for each dataset rightly have to observe strict information governance rules and it is right and proper that any data that might identify an individual is kept strictly confidential. Identifiers may be however be needed to link datasets, before they are removed. For example, data from screening datasets frequently needs to be linked with those generated by the cancer registration service and sometimes with primary care or hospital datasets. The problems appear to arise when one data controller does not accept another's information governance processes. All of the datasets relating to NHS-funded care, including care commissioned by the NHS from independent providers.

In addition to information governance problems, additional barriers may arise when research proposals are submitted to research advisory committees for each of the screening programmes. Again, it is right and proper that the screening programmes should ensure that any research is not going to interfere with the smooth running of the relevant programme, but researchers told us that this can result in additional delays.

The processes described during the course of this review are positively Kafka-esque, with researchers going round and round in circles long after research funding committees have approved the quality of the proposed research and awarded funding. The following two examples set out some researcher experience:

Case study: Breast screening research – a 28 month delay (so far)

This case study outlines the difficulties and frustration experienced by a researcher in attempting to initiate a project requiring attendance data from the NHS Breast Screening Programme to be linked with a local case-cohort study on risk factors and cancer registration. The necessary approvals and contracts were already in place for data linkage of identifiable data within the local study; the research group would be analysing anonymised and non-identifiable data on pre-specified variables, provided by the local study group.

Month 1	Office for Data Release (ODR) were contacted and provided an application form, additional information and guidance.
Month 3	ODR application, research protocol, data specification, ethics, consent and System Level Security Policy (SLSP) were submitted by the research group for review by the Research Advisory Committee (RAC). Review was delayed because of volume and capacity.
Month 4	Study was reviewed by RAC.
Month 5	RAC approval was given.
Month 8	Funding for the project was awarded.
Month 10	ODR requested further details on information and data security, and the data transfer agreement between the Institutions of the local study and the research group. Over this month, there was much discussion around responsibility and 'who is the data processor and data controller'.
Month 11	ODR requested to review the data transfer agreement; no template for this document existed.
Month 12	Research team supplied first draft of data transfer agreement to ODR.
Month 13	ODR provided feedback on data transfer agreement, requesting lots more information.
Month 14	General Data Protection Regulation (GDPR) came into effect.
Month 16	Teleconference held between ODR and the legal departments of the two institutes affiliated with the project application to agree on requirements of data transfer agreement.
Month 16-24	Drafting and feedback process between the institutes and ODR.
Month 24	Final signed and agreed form on Data Access and User Agreement was submitted to ODR. ODR provided a new list of requirements from research group.

Month 25	ODR requested Health Research Authority (HRA) and Research Ethics Committee (REC) approval over and above the ethics approval that was in place which the Joint Research Office Sponsor of the affiliating institute had deemed to be sufficient. HRA/REC approval had not been requested by ODR when ethics had been provided in Month 3. The research group therefore had to resubmit Integrated Research Application System (IRAS) for sponsorship and an application for HRA review.
Month 28	<p>HRA reviewed the application and confirmed that the proposed study did not require a decision from HRA. ODR agreed but requested REC approval and HRA to review the confidentiality advisory group (CAG) approvals in place.</p> <p>HRA are currently reviewing whether CAG and REC approvals are required for data linking, given the local study has CAG approval and the research group will only receive anonymised and processed dataset from the local study group.</p>

Case study: Bowel screening research – a five-year delay (so far)

This research project was originally approved and granted funding by Cancer Research UK in 2014. It has still (in 2019) not cleared all the necessary information governance hoops. The project aims to gain a deeper understanding of the reasons why some people respond to invitations to bowel screening, while others don't. Ultimately, it is hoped that this understanding will lead to initiatives to promote higher uptake. The research will involve combining data:

- on patients' demographics (e.g. socioeconomic status and ethnicity) and their interactions with their GPs, collected by the Clinical Practice Research Datalink (CPRD)
- participation in bowel screening, with data collected by one of the regional bowel screening hubs
- data collected by the National Cancer Registration Service

To do this, approvals have to date been required from:

- an independent scientific advisory committee, taking seven days in 2014
- Public Health England, received in 2017
- The Bowel Cancer Screening Programme Research Advisory Committee, received in 2017
- NHS Digital Data Access Request Service, taking 308 days to complete in 2018
- CPRD, expected by end 2019.

The UK is fortunate to have a cadre of very high-quality researchers, including epidemiologists and behavioural scientists, who are interested in screening research. These researchers have access to funding (particularly for the cancer screening programmes) through bodies such as the National Institute for Health Research (NIHR) and Cancer Research UK, but face multiple barriers in undertaking research once it has been funded. While these problems are not unique to screening, the information governance hurdles do seem to be particularly onerous, largely because of the number of different organisations involved.

RECOMMENDATIONS

This review recommends that:

Recommendation 21: Routine audit data on each of the five adult programmes should be published by NHSE, at least annually, so that the public can be assured that the services are operating as expected. This should include appropriate equality data to support monitoring of uptake in under-served groups.

Recommendation 22: The process for releasing data for research purposes should be reviewed and simplified, with timelines being set for decisions by individual committees, including the Office for Data Release. Further approval processes should be consolidated across different organisations with carefully defined remits documented for all parties, including data sharing arrangements.

GLOSSARY

Key terms	Acronym	Definition
Age extension trial	AgeX	Established in 2009 to test the benefits of extending the breast screening programme to women from age 47 to 73.
Bowel scope	–	A test for people aged 55 where a thin, flexible tube with a camera at the end is used to look inside the bowel.
Care Quality Commission	CQC	The independent regulator of health and adult social care in England.
Commissioning for Quality and Innovation	CQUIN	A Commissioning for Quality and Innovation payments framework encourages care providers to share and continually improve how care is delivered and to achieve transparency and overall improvement in healthcare.
Department of Health and Social Care	DHSC	A Ministerial Department which leads on health and social care, supported by 28 Arm's Length Bodies and other agencies.
Faecal Immonochemical Test	FIT	A revised bowel cancer home testing kit which tests for hidden blood in stool samples, which can be an early sign of bowel cancer.
Guaiac faecal occult blood test	gFOBT	Current home-testing test in use to detect small amounts of blood in the stool, which you would not normally see or be aware of. This is being replaced by FIT (see above).
Health Education England	HEE	Supports the delivery of healthcare and health improvement to the patients and public of England by ensuring that the workforce of today and tomorrow has the right numbers, skills, values and behaviour.
Human papillomavirus testing	HPV testing	HPV primary screening is currently used as the first test on cervical screening samples in some areas of England and is scheduled to be introduced across the country in 2019.

Key terms	Acronym	Definition
Index of Multiple Deprivation	IMD	Official measure of relative deprivation for small areas (or neighbourhoods) in England.
Integrated Care Systems	ICS	An evolution of an STP (see below). An integrated care system is an even closer collaboration with NHS organisations, in partnership with local councils and others, taking collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.
National Audit Office	NAO	Scrutinises public spending for Parliament.
National Health Application and Infrastructure Services	NHAIS	NHAIS is a system of 83 databases of local GP registrations. It is used across the NHS, including for the invite system in cervical screening and for identifying the eligible population in the four screening programmes we have examined.
National Institute for Health and Care Excellence	NICE	A non-departmental Public Body which provides national guidance and advice to improve health and social care.
NHS Digital	NHSD	Supplies information and data to the health service, provides vital technological infrastructure, and helps different parts of health and care work together.
NHS England	NHSE	Leads the National Health Service (NHS) in England. It sets the priorities and direction of the NHS and encourages and informs the national debate to improve health and care.
NHSX	–	This new organisation oversees digital, data and technology for the NHS to deliver the Health Secretary’s Tech Vision, building on the NHS Long Term Plan.
National tariff	–	A set of currencies (e.g. defined episodes of care), prices and rules governing the payments that NHS commissioners make to providers for NHS-funded healthcare (except for primary care services). It is intended to promote high quality care and improve the efficiency with which services are provided. The tariff is set on an annual or multi-year basis.

Key terms	Acronym	Definition
Public Health England	PHE	An executive agency of the Department of Health and Social Care; its responsibilities include supporting local authorities and the NHS to plan and provide health and social care services such as immunisation and screening programmes, and to develop the public health system and its specialist workforce.
Quality and Outcomes Framework	QOF	Part of the General Medical Services (GMS) contract for general practices. It aims to improve the quality of care patients are given by rewarding practices for the quality of care they provide.
Randomised Controlled Trials	RCT	A study in which a number of similar people are randomly assigned to 2 (or more) groups to test a specific drug, treatment or other intervention. One group (the experimental group) has the intervention being tested, the other (the comparison or control group) has an alternative intervention, a dummy intervention (placebo) or no intervention at all. The groups are followed up to see how effective the experimental intervention was. Outcomes are measured at specific times and any difference in response between the groups is assessed statistically. This method is also used to reduce bias.
Round length	–	Screening round length is the interval between the date of a woman's previous screening mammogram and the date of her next first offered appointment. This should be thirty six months.
Section 7A	S7A	Sets out for commissioners and healthcare providers notice of NHS England's commissioning intentions for certain Public Health services, commissioned as part of the NHS Public Health Functions Agreement under s.7A of the NHS Act 2006. This is an annual agreement between the Department of Health and Social Care and NHS England.

Key terms	Acronym	Definition
Screening Quality Assurance Service	SQAS	The role of the Screening Quality Assurance Service is to assess the quality of local screening programmes, monitor compliance with standards, support services with improving quality.
Sustainability and Transformation Partnerships	STP	Created to bring local health and care leaders together to plan around the long-term needs of local communities. They have been making simple, practical improvements like making it easier to see a GP, speeding up cancer diagnosis and offering help faster to people with mental ill health. In some areas, STPs have evolved to become Integrated Care Systems (see above).
Turnaround time (Cervical Screening)	TAT	'Time from screening to receipt of results' is defined as the interval between the date the sample was taken to the date the result is received.
UK National Screening Committee	UK NSC	Advises ministers and the NHS in the four UK countries about all aspects of population screening and supports implementation of screening programmes.

APPENDIX A: FURTHER INFORMATION ON THE ACTIVITY OF THE REVIEW

MEETINGS, ROUNDTABLES AND VISITS SPECIFICALLY CONVENED FOR THIS REVIEW

Meetings and interviews arranged by the review team

A number of meetings and interviews were arranged over the course of this review with a wide range of stakeholders. These included meetings with:

- over 80 representatives from the Department of Health and Social Care and its Arm's Length Bodies, including:
 - Health Education England
 - NHS Digital
 - NHS England and NHS Improvement
 - NHSX
 - Public Health England
 - Care Quality Commission
- around 20 academics including epidemiologists, behavioural scientists and academic GPs.
- 8 representatives from the Royal Colleges and other professional societies, including:
 - Association of Directors of Public Health
 - British Medical Association
 - British Society of Gastroenterology
 - Royal College of General Practitioners
 - Royal College of Pathologists
 - Royal College of Physicians
 - Royal College of Radiologists
 - Society and College of Radiographers

- 11 industry representatives, as follows:
 - Babylon
 - Deep Mind
 - Fujifilm
 - Hitachi
 - IHPN
 - InHealth
 - iPlato
 - Kheiron Medical
 - Medical Imaging Partnership
 - Preventx
 - Roche

Roundtables/large groups convened for this review

A number of roundtables and large group sessions were also convened by external organisations for the purposes of the review, which collectively involved over 400 contributors. These were as follows:

- Cancer Research UK
 - Roundtable session
 - Diagnostics team session
 - Lower levels of literacy consultation
 - GP session
 - Roundtable with non-cancer charities
 - Patient Involvement Sounding Board
- Public Health England
 - Roundtable
 - Sheffield team
- Royal college of Radiologists
 - Royal Lung cancer screening group
- NHS England and Improvement
 - IT workshop (with NHSX)
 - Roundtable session
 - Kent, Surrey & Sussex local commissioning team

- Public Health England
 - Screening Quality Assurance Service (SQAS)
- Royal College of Pathologists
 - Conference
- Members of Parliament

Visits

The review team were also invited to visit a number of local services and trusts. These were as follows:

- Addenbrooke's Hospital Cambridge:
 - Breast screening team
 - Bowel screening team
 - Cervical screening team
 - Diabetic eye screening team
- Bowel Cancer Screening Southern Hub, Guildford
- King's College Hospital breast screening service
- London Breast Screening Hub, Edgware
- PHE Screening Quality Assurance Service, Manchester
- Rapid Access Diagnostic Centre, Guy's Hospital
- The Jarvis Centre/InHealth breast screening centre, Guildford

EXTERNAL MEETINGS ATTENDED BY THE REVIEW

The Chair and Review Team members were additionally invited to attend a number of pre-existing external meetings over the course of the review as follows:

- AgeX trial management group
- Advisory Committee on Breast Screening
- Advisory Committee on Cervical Screening
- Bowel Screening Advisory Committee
- Department of Health and Social Care Board
- Diabetic Eye Screening Advisory Committee
- NHSI Imaging Board
- NHSI Pathology Improvement Board
- PHE/NHSE Joint Heads of Public Health and SILs
- Section 7A Assurance Meeting

- Southern Screening Improvement Leads and Screening Improvement Managers
- Transforming Cancer Services Team/NHSE London Cancer Screening Improvement Board
- Tripartite Directors' Meeting
- UK Chief Medical Officers (Four countries)
- UK National Screening Committee, and its Adult Reference Group

Conferences

The review team also attended the following conferences:

- Cancer Research UK Early Diagnosis Conference
- Health Service Journal Cancer Summit
- TCST Faster Diagnosis Standard Conference

SUMMARY OF THE CALL FOR EVIDENCE

An online call for evidence on problems and solutions in various aspects of cancer screening was open between 21 February and 18 April 2019. The call was distributed by the secretariat team to members of the cancer and wider health community and promoted through Cancer Research UK's Patient Involvement Network to gather evidence from non-specialists and people affected by cancer. It was promoted through Public Health England's screening blog.

The call received over 110 submissions from a wide range of stakeholders which were recorded and analysed by the secretariat team. We would like to thank all who submitted written pieces of evidence.

The following groups of individuals provided submissions to the call for evidence:

- Members of the general public and people affected by cancer
- Academic and clinical researchers
- Service providers, including programme managers of screening services
- Clinicians, including surgeons, radiologists and physicians

The following organisations submitted responses to the call for evidence:

- Charities (Roy Castle, Breast Cancer Care/Breast Cancer Now, PHG Foundation, Breast Density Matters UK, Jo's Cervical Trust, HealthWatch UK, Action on Smoking and Health (ASH), Prostate Cancer UK, Teenage Cancer Trust, Bowel Cancer UK, Cancer Research UK)
- Screening Units
- Cancer Alliances
- National Institute for Health and Care Excellence

SECRETARIAT TEAM

The Chair was supported in his work by the following members of the Secretariat team:

Jo Aracena

Andrew Boaden

Sam Cramond

Eleanor Gray

Zara Gross

Ruiraidh McAndrew

Fiona Pearson

Kathryn Whitmore

APPENDIX B: POPULATION SCREENING PROGRAMMES IN ENGLAND

SELECTION CRITERIA FOR POPULATION SCREENING PROGRAMMES

The criteria upon which the UK National Screening Committee decide whether a disease or condition should be considered for a population screening programme are based on those originally introduced by Wilson and Jungner in their 1968 “*Principles and Practice of Screening for Disease*” paper as commissioned by the World Health Organisation¹⁰¹. The criteria were last updated in 2015 following a structure and process review and are set out below¹⁰². This is followed by a complete list of current population screening programmes in England (as at August 2019):

The condition

1. The condition should be an important health problem as judged by its frequency and/or severity. The epidemiology, incidence, prevalence and natural history of the condition should be understood, including development from latent to declared disease and/or there should be robust evidence about the association between the risk or disease marker and serious or treatable disease.
2. All the cost-effective primary prevention interventions should have been implemented as far as practicable.
3. If the carriers of a mutation are identified as a result of screening the natural history of people with this status should be understood, including the psychological implications.

The test

4. There should be a simple, safe, precise and validated screening test.
5. The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.
6. The test, from sample collection to delivery of results, should be acceptable to the target population.

101 Wilson JMG, Jungner G. Principles and practices of screening for disease. Geneva, Switzerland: World Health Organization; 1968

102 Gov.uk. 2013. Evidence review criteria: national screening programmes. [ONLINE] Available at: <https://www.gov.uk/government/publications/evidence-review-criteria-national-screening-programmes>.

7. There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals.

8. If the test is for a particular mutation or set of genetic variants the method for their selection and the means through which these will be kept under review in the programme should be clearly set out.

The intervention

9. There should be an effective intervention for patients identified through screening, with evidence that intervention at a pre-symptomatic phase leads to better outcomes for the screened individual compared with usual care. Evidence relating to wider benefits of screening, for example those relating to family members, should be taken into account where available. However, where there is no prospect of benefit for the individual screened then the screening programme should not be further considered.

10. There should be agreed evidence based policies covering which individuals should be offered interventions and the appropriate intervention to be offered.

The screening programme

11. There should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity. Where screening is aimed solely at providing information to allow the person being screened to make an “informed choice” (such as Down’s syndrome or cystic fibrosis carrier screening), there must be evidence from high quality trials that the test accurately measures risk. The information that is provided about the test and its outcome must be of value and readily understood by the individual being screened.

12. There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public.

13. The benefit gained by individuals from the screening programme should outweigh any harms, for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications.

14. The opportunity cost of the screening programme (including testing, diagnosis and treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (value for money). Assessment against this criteria should have regard to evidence from cost benefit and/or cost effectiveness analyses and have regard to the effective use of available resource.

Implementation criteria

15. Clinical management of the condition and patient outcomes should be optimised in all health care providers prior to participation in a screening programme.

16. All other options for managing the condition should have been considered (such as improving treatment or providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.
17. There should be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards.
18. Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be available prior to the commencement of the screening programme.
19. Evidence-based information, explaining the purpose and potential consequences of screening, investigation and preventative intervention or treatment, should be made available to potential participants to assist them in making an informed choice.
20. Public pressure for widening the eligibility criteria for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.

NATIONAL SCREENING PROGRAMMES IN ENGLAND AS AT AUGUST 2019

Condition	Type
Downs Syndrome	Antenatal
Fetal anomalies	
Hepatitis B	
Human immunodeficiency virus	
Neural tube defect	
Sickle cell and Thalassaemia	
Syphilis	
Trisomy 18 (T18) and Trisomy 13 (T13)	
Congenital cataracts	Newborn
Congenital heart disease	
Congenital hypothyroidism	
Cryptorchidism	
Cystic Fibrosis (newborn)	
Development dislocation of the hip	
Glutaric aciduria type 1 (GA1)	
Homocystinuria (HCU)	
Hearing (newborn)	
Isovaleric acidaemia (IVA)	
Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)	
Maple syrup urine disease (MSUD)	
Phenylketonuria (PKU)	
Sickle cell disease (newborn)	
Growth	Child
Hearing (child)	
Vision defects	
Diabetic eye	Children and young people and Adult
Abdominal Aortic Aneurysm (AAA)	Adult
Bowel cancer	
Breast cancer	
Cervical cancer	

APPENDIX C: NHS ABDOMINAL AORTIC ANEURYSM SCREENING PROGRAMME

THE NEED FOR SCREENING

The aorta is the main blood vessel that runs from the heart through the chest and abdomen. In some people, as they get older, the wall of the aorta can become weak. It can then expand and form an aneurysm. Aneurysms are usually asymptomatic, but large aneurysms can rupture. If they do so, the risk of death is high (around 85%).

Aneurysms are more common in men than women and amongst smokers and those with high blood pressure. People with a family history of abdominal aortic aneurysm are also at elevated risk.

THE SCREENING PROGRAMME

Screening for abdominal aortic aneurysm (AAA) was first approved in 2008, when the results of randomised trials had shown that it would reduce mortality from ruptured aneurysm and be cost effective¹⁰³.

The AAA screening programme became fully operational from 2013. It is targeted exclusively at men aged 65 as they have a much higher risk of AAA than women. Men older than 65 can self-refer. It is estimated to cost £14 million per year¹⁰⁴.

Deaths from AAA were already falling when the screening programme was introduced, making formal evaluation of the impact of the programme complex. However, mortality has shifted to peak at older age, which may reflect the impact of the programme.

Providers of screening

At the time of publication, screening was being provided by 39 providers, of which 38 are NHS providers. These are closely linked with NHS vascular surgery services. One programme in London is provided by an independent sector provider (InHealth).

103 Screening men for abdominal aortic aneurysm: 10 year mortality and cost effectiveness results from the randomised Multicentre Aneurysm Screening Study BMJ 2009; 338 doi: <https://doi.org/10.1136/bmj.b2307> (Published 24 June 2009) Cite this as: BMJ 2009;338:b2307.

104 As advised by NHS England/Improvement based on actual 2018/19 expenditure and pending publication of Annual Accountability Statement for 2018/19.

THE SCREENING PROCESS

Invitation

Men aged 65 are invited for a one-off ultrasound scan of their aorta. Depending on the diameter of their aorta they are either reassured (less than 3cm), invited to annual scans (3cm-4.4cm), invited to quarterly scans (4.5cm-5.4cm) or referred to a specialist surgeon within two weeks due to a high risk of rupture (5.5cm or more).

The screen

Screening involves an ultrasound of the aorta. This is painless but involves some cold gel being put on the abdomen. It is undertaken in community locations, which are usually relatively close to a person's home. Screeners are specifically trained to undertake this imaging, which takes less than 10 minutes. Patients are informed of the results straight away. The diameter of the aorta is measured, and patients are classified as follows: < 3cms – Normal; 3.0-4.4cms – small aneurysm; 4.5-5.4cms – medium aneurysm; > or = 5.5cms – large aneurysm.

Follow up

Participants are told the results of their screen straight away during their screening attendance.

People with normal findings are not followed up. Those with small aneurysms are placed under annual surveillance and those with medium aneurysms are called back at three monthly intervals. Those with large aneurysms are referred urgently to vascular surgery services. Although surgery carries risks, the risk of a large aneurysm bursting is much higher. Approximately 1 in 80 men are found to have small aneurysms, 1 in 200 are found to have medium aneurysms and 1 in 1,000 have large aneurysms.

Drivers with large aneurysms have to notify DVLA. Car drivers with aneurysms larger than 6.5cms have their licences suspended and coach and lorry drivers have their licence suspended if their aneurysm measures more than 5.5 cms. Licences can be reinstated after successful surgery.

CURRENT PERFORMANCE (AS AT 2017/18)¹⁰⁵

285,693 men were eligible for screening, of whom 99.4% were offered an initial screen. 38 of the (then) 41 providers achieved offer rates of over 99%.

Uptake is high with 80.5% of eligible men (approximately 230,000) tested within a year and three months of being invited for screening.

Coverage has increased from 2013/14 to 2017/18, although it slipped in London in 2017/18 during a recommissioning process. It was lowest in the most deprived decile (70.5%) and highest in the most affluent decile (87.6%). However, detection of aneurysms is highest in the most deprived populations.

¹⁰⁵ Public Health England. 2018. PHE Screening - AAA screening annual data published for 2017 to 2018. [ONLINE] Available at: <https://phescreening.blog.gov.uk/2019/01/31/aaa-screening-annual-data-published-for-2018-to-2018/>. [Accessed 18 September 2019].

Surveillance

12,028 men were due for annual surveillance of whom 11,800 were offered an appointment within 6 weeks of the due date (98.1%). 91.3% had a conclusive test within 6 weeks of due date.

8,376 men were due for quarterly surveillance of whom 8,205 were offered it within 4 weeks of the due date (98.0%). 91.9% had a conclusive test within 4 weeks of the due date.

Findings

The proportion of patients found to have an aorta larger than 3cms has fallen since 2013/14 from around 1.2% to around 1%.

The proportion of these people with an aortic diameter greater than 5.5 cm who were seen by a vascular specialist within two weeks was 94.3%.

793 patients were referred for possible surgery, of whom 84 were deemed unsuitable and 14 declined surgery. 619 of the remaining 695 (89.1%) underwent surgery. Just over half of these patients underwent open surgery, with the others undergoing endovascular repair. Just over half of the operations occurred within 8 weeks of referral. 30-day mortality following surgery was 1.13%.

STRENGTHS

Randomised controlled trials (RCTs) have demonstrated the impact AAA screening has in reducing mortality of those screened^{106, 107, 108}. An article published in the Journal of Vascular Surgery in 2013 looked at the implementation of the AAA NHS screening programme and supported the findings of these studies¹⁰⁹. The authors anticipated that the programme would reduce the amount of premature deaths by up to 50% and continue to remain cost effective.

The AAA service is generally performing very well and achieving many of the key performance indicators. The close linkage between the AAA screening programme and vascular surgical services is a key strength.

The bespoke AAA IT system operates well for call and recall and good links have been established with the vascular surgery registry. However, linkage with GP systems and with data from NHS trusts is suboptimal.

106 Lindholt J, Juul S, Fasting H, Henneberg E, Hospital Costs And Benefits Of Screening For Abdominal Aortic Aneurysms. Results From A Randomised Population Screening Trial (2002)

107 The Influence of screening on the incidence of ruptured abdominal aortic aneurysms (1999) [Teun B.M. Wilmink](#), MD, FRCS [Clive R.G. Quick](#), MS, FRCS [Catherine Sff. Hubbard](#), FRCR [Nicholas E. Day](#), PhD

108 The Multicentre Aneurysm Screening Study (MASS) Into The Effect Of Abdominal Aortic Aneurysm Screening On Mortality In Men: A Randomised Controlled Trial (2002) [Ashton HA](#), [Buxton MJ](#), [Day NE](#), [Kim LG](#), [Marteau TM](#), [Scott RA](#), [Thompson SG](#), [Walker NM](#); [Multicentre Aneurysm Screening Study Group](#)

109 Implementation Of The National Health Service Abdominal Aortic Aneurysm Screening Program In England (2013) Davis, M. Harris, M. Earnshaw, Jonothan

OPPORTUNITIES

The following opportunities have been identified during the course of this review to further improve the uptake, coverage and functioning of the AAA screening programme:

- Although uptake and coverage are generally high there is still scope for improvement. Phone calls to patients have been shown to increase uptake by some services, but these are time consuming and expensive.
- Text reminders have not yet been systematically tested for AAA screening but are known to increase uptake in other screening programmes.
- A questionnaire survey in one part of the country has indicated that out of hours appointments would be welcomed.
- Although the IT system is generally considered good, improvements are needed to make it more patient centred (e.g. online booking of appointments) and to improve the interfaces with other NHS systems.
- Service providers have commented that the approach to commissioning and recommissioning varies across the country. Consistency would be welcomed.
- Patients with enlarged aortas may be kept under surveillance for years until they reach an aortic diameter of 5.5cms. More should be done to optimise their fitness for surgery during this time (prehabilitation).
- Research and evaluation of the AAA screening programme is not as well supported as that for the cancer programmes.

APPENDIX D: NHS BOWEL CANCER SCREENING PROGRAMME

THE NEED FOR SCREENING

Randomised controlled trials undertaken in England, Denmark, Sweden and Minnesota, USA from the mid-1970s onwards and reported in the 1990s, showed that two yearly screening using Guiac Faecal Occult Blood Testing (gFOBT) in people aged 50-74 years can reduce mortality from colorectal (bowel) cancer by around 16% (or 23% in those actually screened)¹¹⁰.

Following these results, a large-scale pilot was commissioned in the West Midlands and a region of Scotland to assess the uptake, acceptability to the public and impact on the NHS of gFOBT screening. This demonstrated the feasibility of screening in the NHS and showed that close to 60% of those invited participated. Results were closely in line with those from the Nottingham trial. Following evaluation of the pilots, the UK National Screening Committee (UK NSC) recommended gFOBT for screening men and women aged 50-74 in July 2003¹¹¹. The evaluation of the pilot also recommended that consideration should be given to the use of immunochemical tests.

THE SCREENING PROGRAMME

The NHS Bowel Cancer Screening Programme (BCSP) began in 2006 and initially involved men and women aged 60-69. By 2008, over 2 million people had been invited to participate. Age expansion to people aged 70-74 was announced in the Cancer Reform Strategy (2007), with the first wave of expansion across screening centres starting in January 2010. Another one-off screening test offered to men and women at the age of 55 in some parts of England. The bowel screening programme costs £211 million per year¹¹². There are two elements to the current programme:

- **Faecal Immunochemical Test** In 2015, the UK NSC recommended a change from the gFOBT to the Faecal Immunochemical Test (FIT)¹¹³. This is a more

110 Towler B, Irwig L, Glasziou, P., 1998. A systematic review of the effects of screening for colorectal cancer using the faecal occult blood test, Hemoccult. BMJ, [Online]. 317(7158), 559-565. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC28648/>

111 Public Health England. 2003. UK NSC recommendation on Bowel Cancer screening in adults. [ONLINE] Available at: <https://legacyscreening.phe.org.uk/bowelcancer>

112 As advised by NHS England/Improvement based on actual 2018/19 expenditure and pending publication of Annual Accountability Statement for 2018/19 (Bowel scope £85m; gFOBT £126m). Note these costs do not reflect the implementation of FIT 120 or the continued roll out of bowel scope.

113 UK National Screening Committee, (2016). Screening in the UK: Making effective recommendations, 2015 to 2016.

sensitive test and is easier for participants as they only have to collect a single stool sample, rather than three. In 2004, evidence from large scale pilots in England showed that uptake was around 7% higher than for FOBT, reflecting the increased acceptability of the test¹¹⁴. Uptake has increased by 8.5% since FIT was introduced in Scotland in November 2017, with the biggest improvement in participation seen amongst those living in the most deprived areas – up from 42.0% to 51.8%¹¹⁵. Roll out of FIT in England has been delayed at least in part due to challenges with procurement of the FIT test kits. However, from June 2019, the changeover from gFOBT to FIT was implemented across England.

- **Bowel scope** In 2011, the UK NSC recommended an additional bowel screening programme (Bowel scope or flexible sigmoidoscopy), following publication of a randomised controlled trial conducted in the UK. The bowel scope programme has taken much longer than anticipated to be rolled out. At present, patients from around half of all GP practices in England are being invited for bowel scope screening.

Providers of screening

FIT is undertaken at home and the results are posted and processed by one of five screening hubs across England.

THE SCREENING PROCESS (FIT ONLY)

Identification

At present, FIT is aimed at men and women aged 60 to 74, though the plan is to reduce the starting age to 50. Patients aged 60-74 are sent an information leaflet and invitation letter, followed one week later by a FIT kit. This happens at two-yearly intervals.

The screen

This requires a single stool sample only, which is then returned by post to one of five screening hubs across England. Samples are quantitatively analysed in the laboratory, with samples recorded as having 120 micrograms of haemoglobin per gram of stool being recorded as positive. Patients should receive their result (positive or negative) within two weeks of the laboratory receiving the kit. Around 2% of patients can be expected to have a positive result.

Follow up

Patients with a positive result are invited to one of 65 bowel screening centres for colonoscopy. Prior to colonoscopy, the procedure is explained to them by a specialist screening practitioner (SSP) and their fitness for the procedure

114 BMJ 2004;329:133 Results of the first round of a demonstration pilot of screening for colorectal cancer in the United Kingdom BMJ 2004; 329 doi: <https://doi.org/10.1136/bmj.38153.491887.7C> (Published 15 July 2004)

115 ISD Scotland. 2019. Scottish Bowel Screening Programme Statistics. [ONLINE] Available at: <https://www.isdscotland.org/Health-Topics/Cancer/Publications/index.asp#2347>. [Accessed 17 September 2019].

is assessed. Those deemed unfit may be referred for CT colonography (a radiological examination). Prior to colonoscopy, they are given laxative medication to clear the bowel.

Colonoscopy involves insertion of a long flexible tube with a light source (colonoscope) via the anus into the large bowel, allowing a highly trained endoscopist to visualise the lining of the entire large bowel. Around 10% of patients undergoing screening can be expected to have a cancer and a larger number (around 30%) will have polyps detected. Polyps can generally be removed during the colonoscopy. If a cancer is detected, the patient may need to be referred for surgery.

Bowel scope

This programme is aimed at people aged 55 and involves a thin flexible tube being introduced into the lower end of the bowel allowing the operator to see any small growths or polyps, which could turn into cancer. These can then be removed, thereby lowering the risk of developing cancer and reducing mortality. Some patients with polyps may then be recommended to have a colonoscopy.

In 2018/19, around 385,000 were invited to testing, of which around 182,000 underwent a flexible sigmoidoscopy (47% uptake). This is a one-off test.

CURRENT PERFORMANCE (AS AT 2017/18)¹¹⁶

Bowel screening met its lower threshold targets in 2017/18 but did not meet its standard target. Performance against bowel screening standards is improving and is expected to improve further through implementation of the FIT.

On gFOBT, around 4.4 million people were invited for screening in 2017/2018, of whom 2.5 million people (57.7%) returned a sample. On bowel scope, around 337,500 were invited to testing in 2017/18, of which around 155,600 (46%) underwent a flexible sigmoidoscopy.

100% of the bowel screening (gFOBT) test kits sent by participants were reported within two weeks of being received by the reporting laboratory. For those with positive results, 98.8% were offered a fitness assessment with a specialist screening practitioner within the required two weeks of their referral date. The time from that initial assessment to a diagnostic test (usually colonoscopy) should be less than 14 days from this assessment. Approximately 82.9% of patients were offered a diagnostic test in that time.

An important measure of quality of colonoscopy is the adenoma detection rate. This is the proportion of all patients undergoing colonoscopy who have at least one histologically confirmed adenoma. At a national level, the detection rate was 52.4%, but varied between colonoscopy centres from 43.7% to 67.1%.

116 Public Health England. 2018. Public Health Profiles - Cancer Services. [ONLINE] Available at: <https://fingertips.phe.org.uk/profile/cancerservices>

STRENGTHS

Bowel cancer screening is estimated to save around 2,400 lives per year. Performance against bowel screening standards is improving and is expected to improve further through implementation of the FIT, but from a low starting point.

As one of the more recent screening programmes, bowel screening benefits from a single IT management system that covers the whole country. This means that any update to the system can be managed centrally and the screening record will follow the patient if they move from one part of the country to another.

OPPORTUNITIES

The following opportunities have been identified during the course of this review to further improve the uptake, coverage and functioning of the bowel screening programme:

- **Expansion of approach** In August 2018, Ministers agreed that the starting age for bowel screening should be lowered to 50 years. It is also planned that over time the sensitivity level of the FIT screening test will be increased, thereby identifying a higher proportion of patients with cancers or polyps. Colonoscopy capacity is a major rate limiting factor. Final decisions on the timescales for extension to lower ages and on increasing sensitivity are awaited. A sensitivity level of 120ug/g is currently set, which is around 20% more sensitive than the previous gFOBT.
- **Workforce** Bowel cancer screening is resource intensive particularly within endoscopy and pathology and there is a need for a highly specially trained workforce and facilities. The main challenge for bowel screening is to lower the starting age from 60 to 50 years and to increase the sensitivity threshold of the FIT as quickly as possible, in line with recommendations of the UK National Screening Committee. While the five screening hubs have the capacity to process more FIT tests, optimising bowel cancer screening will have inevitable consequences for workforce.
- **Demand for screening colonoscopy** Major shifts in the indications for colonoscopies are expected in the near future (see Chapter 10), but not necessarily an overall increase in demand. Since we know that lowering the age and threshold for FIT testing will improve the effectiveness of the programme – and save more lives – the system must urgently consider and plan for this. The full impact on diagnostic and symptomatic services must be understood to enable screening hubs and centres to prepare for full implementation, building on activity already being taken forward by Health Education England (HEE). Colonoscopy activity will need to be very closely managed over the next few years.

APPENDIX E: NHS BREAST SCREENING PROGRAMME

THE NEED FOR SCREENING

About 1 in 8 women in the UK are diagnosed with breast cancer during their lifetime. If it's detected early, treatment is more successful and there's a good chance of recovery. As the likelihood of getting breast cancer increases with age, all women aged from 50 to their 71st birthday, and registered with a GP are automatically invited for breast cancer screening every 3 years.

THE SCREENING PROGRAMME

The NHS Breast Screening Programme (NHSBSP) started in 1988 following the publication of the Forrest report¹¹⁷. Initially, it was aimed at women aged around 50 to 64 years with women being invited every three years (i.e. a total of five invitations). In the mid-2000s, the programme was extended to involve women up to around 70 years (i.e. each woman would normally be offered seven invitations). This involved a major increase in workload and was achieved through the introduction of a 'skillmix' programme. Some radiographers were trained to become advanced practitioners or consultant radiographers, taking on additional duties including reporting of mammograms. Assistant practitioners were also trained to undertake some of the mammography workload.

A major review of the research evidence on the effectiveness was undertaken by Professor Sir Michael Marmot in 2012¹¹⁸, jointly commissioned by the Department of Health and Cancer Research UK. This confirmed that breast screening reduces the risk of dying from breast cancer, but also highlighted the fact that some women may have a breast cancer diagnosed that would not have caused any problem during their lifetime (so called overdiagnosis).

Providers of screening

There are currently 78 providers of breast screening services in England, of which 75 are directly hosted by NHS trusts. Three are provided by an independent sector provider (InHealth) on behalf of the NHS. The populations served by these services varies quite widely. Providers generally have one or more static units and mobile vans in order to provide screening reasonably close to people's homes.

117 Breast Cancer Screening: Report to the Health Ministers of England, Wales, Scotland and Northern Ireland by a Working Group Chaired by Professor Sir Patrick Forrest (1986).

118 Marmot, M., 2012. The benefits and harms of breast cancer screening: an independent review. *Lancet*, [Online]. 380 (9855), 1778-1786. Available at: <https://www.thelancet.com/action/showPdf?pii=S0140-6736%2812%2961611-0> [Accessed 17 September 2019].

THE SCREENING PROCESS

Identification

Breast screening is currently offered to women aged 50 to their 71st birthday. Women who are eligible for breast screening are identified through GP registration systems, and selected in batches relating to their GP practice. This allows women to be invited when a mobile breast screening van would be in their vicinity. Invitations are based on year of birth, so some women receive their first invitation when they are still aged 49 years, while others are first invited when they are 52. All women should receive their first invitation before they are 53.

Once a batch has been identified, women are invited by letter with an appointment date and time. Women will normally receive the letter 30 days before the appointment date, which can be changed if they are unable to attend. A second timed appointment letter is sent to women who do not attend their first appointment. If they subsequently do not attend a second appointment then they will receive an open invitation letter asking them to call their local breast screening service to directly book an appointment.

Most appointments are provided within normal working hours (Monday to Friday). However, some screening units also provide evening or weekend appointments. Anecdotal reports indicate that these are welcomed by some women.

Some breast screening services send text reminders. However, this usually only applies to second and subsequent screening rounds, as the screening services do not have routine access to a patient's mobile phone number in advance of their first attendance.

The screen

All X-ray images of the breast (mammograms) are now digital, with images of each breast being taken in two planes. Screening mammograms are reported separately by two individuals (breast radiologists or radiographers with special training). If they disagree on the findings the images are further reported either by a third reader (an individual) or a consensus (a group of readers), a radiologist within the group of readers will make the decision as to whether or not to recall the woman based on the reported mammography findings.

Follow up

Women with normal mammograms should be called for their next screening within 36 months. This interval is referred to as the 'roundlength'.

Women whose mammograms are abnormal are recalled for further assessment. They are usually seen in a static unit which has additional facilities. For example, they may need further mammograms, ultrasound or a biopsy. The interval between abnormal mammography and further assessment should be no longer than three weeks. Women who are found to have breast cancer are referred to a specialist cancer team for treatment.

CURRENT PERFORMANCE (AS AT 2017/18)¹¹⁹

2.89 million women aged 45 years and over¹²⁰ were invited for screening, a decrease of 2.4% from the previous year. The exact reason for this decrease is not known.

A total of 2.14m women were screened in 2017/18. This figure includes those aged 47-49 and over 70 in the AgeX trial and women over 70 who self-refer. This is a decrease of 2.8% from 2016/17.

- Uptake of routine invitations in the core programme (50-70) was 70.5% (1.79m of the 2.89m invited), a decrease from 71.1% in 2016/17 and from 73.2% in 2007/08. Within this:
 - Uptake varied by region, with London being the lowest (63.3%) and East Midlands being the highest (73.6%).
 - Uptake has fallen markedly amongst those receiving a first invitation for screening (from 68.1% in 2007/08 to 60.0% in 2017/18).
 - Uptake varied between breast screening units. 14/79 recorded uptake above 75%, with 18 below 70%.
- Two thirds (66.7%) of the women who were invited were previous attenders who had attended within the previous five years, with a further 11.2% who had previously been screened but more than five years previously.
- Only 60% of women who received their first invitation were screened, compared with 86.3% of those who had been screened within the last five years. Uptake was lowest amongst those who received a routine invitation having failed to respond to a previous invitation.

Note: Women outside the core age range (50-70 years) can be screened without an invite through self/GP referrals, or may be invited as part of a research trial. The number of women invited for breast screening is presented for the '45 years and over' age group in order to capture the full activity of the programme.

Coverage (a measure of the proportion of eligible women in the population aged 53-70 who had been screened within the previous 3 years) was 74.9% at 31 March 2018, compared to 75.4% in 2016/17 and 75.9% in 2007/08. National coverage peaked at 77.2% in 2011/12. Within this:

- Coverage varies across the country ranging from 69.3% in London to 78.4% in the East Midlands.
- Seven Local Authorities reported coverage of 80% or more, while 35 of the 150 reported coverage below 70%.

¹¹⁹ NHS Digital Breast screening Programme report published 28 February 2019, <https://files.digital.nhs.uk/60/77/DCCC/breast-screening-programme-eng-2017-18-report.pdf>

¹²⁰ Women outside the core age range (50-70 years) can be screened without an invite through self/GP referrals, or may be invited as part of a research trial. The number of women invited for breast screening is presented for the '45 years and over' age group in order to capture the full activity of the programme.

In 2017/18, 95.5% of patients who underwent screening mammography received their results within two weeks. For those with abnormal findings at mammography, 91.2% were offered an attendance within three weeks against an acceptable standard of 98%.

7.3% of women attending screening for the first time were referred for assessment, compared with 3.1% of those screened within the last five years. Nearly half of those referred for assessment underwent either a core biopsy, a fine needle aspiration biopsy or an open biopsy.

18,001 women had cancers detected by the programme, a rate of 8.4 cases per 1,000 women screened. The rate increased with age (6.2 per 1,000 in women aged 45-49 and 14.6 per 1,000 in women aged over 70). 14,141 (78.6%) of the cancers were invasive, with just over half (7,223) of these being small (<15mm). 3,851 (21.4%) of the cancers were non-invasive or micro-invasive.

8% of women waited more than 36 months between breast screening appointments (roundlength). 22 of 79 providers did not meet the lower threshold roundlength target of inviting at least 90% of eligible women for a screening appointment.

Screening of women at high risk of breast cancer

Experimental statistics on screening for higher risk women were reported by NHS Digital for the first time in February 2019. High-risk women are those who have been assessed by a specialist in genetics or oncology as being at considerably higher risk than women in the general population. These figures do not include those at 'moderately' increased risk, who are currently managed outside the NHS breast screening programme by local breast cancer teams.

A total of 6,510 high-risk women were screened in 2017/18. Of those, 2,047 had a BRCA2 mutation, 1,893 BRCA1, 1,355 were judged to be at equivalent risk but had not been tested and 1,101 had had previous supradiaphragmatic radiotherapy. The remaining 114 patients had other rarer conditions.

STRENGTHS

Coverage of breast screening has decreased over the years, but is still reasonably good in comparison with that in other developed countries.

Double reading of mammograms by highly trained staff ensures that recall rates are kept low, while rates of interval cancers (those that are diagnosed symptomatically before the next planned screening) are kept low.

Some women at very high risk of breast cancer (e.g. because they carry an abnormal gene) are screened through the breast screening programme. Screening for these individuals starts at an earlier age and is done more frequently than for those at average risk. Their screening may also involve magnetic resonance imaging (MRI).

OPPORTUNITIES

The following opportunities have been identified during the course of this review to further improve the uptake, coverage and functioning of the breast screening programme:

- **Targeted screening** Women at moderately increased risk of breast cancer are not currently screened through the NHSBSP, but this is left to individual NHS trusts to arrange. There is widespread consensus that breast screening should become more targeted on the basis of an individual's risk. Genomics, family history and breast density (as measured on mammography) provide opportunities for risk stratification. Women identified as being at elevated risk of breast cancer should then be offered tailored screening within the NHS breast screening programme.
- **Age extension** A major trial (AgeX) is currently underway within the screening programme to assess the potential benefits of extending the age range to include 47-73 year olds. Women over 70 years can already self-refer, though in practice the numbers who do so are small.
- **IT** The IT systems on which breast screening relies are very old and are almost universally described as 'clunky'. IT systems hosted by individual trusts are prone to breakdown. Poor IT makes systematic assessment of the programme very difficult. Sharing of digital images between locations for example is currently very limited. This hampers sharing of reporting workloads between sites. See further information in Appendix H.
- **Capacity** The breast screening workforce is aging at a time when the eligible population for screening is increasing. Some equipment and some mobile vans are well over 10 years old. Urgent measures are needed to ameliorate these problems and might include:
 - A new grade of associate mammographer is being developed by Health Education England, which could also help with workforce problems.
 - Assistant practitioners currently work alongside registered radiographers on mobile vans but are not allowed to work autonomously. A proposal to allow them to do so is being considered.
 - Artificial Intelligence systems are at an advanced stage of development. These have the potential to reduce the need for two humans to report all mammograms and thus to ameliorate the workforce shortages.
- **Improving uptake** Women should be offered the opportunity to attend screening at times and places they find convenient. Financial incentives should be offered to screening services which adopt this approach and can demonstrate increased uptake. Examples are set out in Chapter 7.

APPENDIX F: NHS CERVICAL SCREENING PROGRAMME

THE NEED FOR SCREENING

The cervical screening programme was established in 1988 and is offered to women aged 25 to 64 (every three years to women aged 25 to 49 and every five years from the ages of 50 to 64). The programme is estimated to cost £185 million per year, including sample taking, laboratory costs and colposcopies¹²¹.

It consists of 12 tests in a lifetime (assuming standard intervals and no additional tests needed). It started as a 'smear' test, then liquid based cytology and is now transitioning to primary HPV testing (with all services to have transitioned by December 2019). Cervical screening is estimated to save around 5,000 lives per year¹²².

THE SCREENING PROGRAMME

The 'Pap' smear for identifying cervical abnormalities was originally developed by Georgios Papanicolaou in the 1940s. Initially, it was used somewhat sporadically in the NHS and a formal screening programme, involving call and recall of women at set intervals, was only introduced in 1988.

In the early years of the programme, a sample was taken from the cervix and smeared onto a glass slide. Between 2004 and 2009, a new process was introduced called 'liquid based cytology' and resulted in a very significant reduction in the proportion of women having inadequate samples taken and, therefore in the need for women to have repeat sampling.

Providers of screening

The large majority of cervical samples are taken in primary care by trained sample takers (often nurses). Other samples are taken in community clinics, sexual health services, NHS hospitals or by private providers. Until recently, cervical samples have been sent to one of 46 laboratories, where the primary test has been cytology (i.e. looking at cervical cells under a microscope).

121 As advised by NHS England/Improvement based on actual 2018/19 expenditure and pending publication of Annual Accountability Statement for 2018/19.

122 Peto, J. (2004). The cervical cancer epidemic that screening has prevented in the UK. *The Lancet*. 2004; Jul 17-23;364(9430):249-56. <https://www.ncbi.nlm.nih.gov/pubmed/15262102>

Further planned developments

Following research evidence and extensive piloting, the UK National Screening Committee (UK NSC) recommended a major change to the programme in 2016¹²³. This approach is now being rolled out. By the end of 2019, all samples will primarily be tested for the HPV virus, with cytological testing being reserved for those that are HPV positive. The proportion of cases that will need cytological testing is expected to decrease by 85%. This approach has been shown to be more sensitive and should save more lives. HPV and cytology testing will be undertaken in one of eight (rather than 46) laboratories. The aim of this is to maintain a sufficient throughput of cytology to maintain expertise amongst cytologists.

The HPV vaccination programme

The very large majority of cases of cervical cancer are due to infection with a high-risk type of Human Papilloma Virus (HPV), especially types 16 and 18. A vaccination programme against these subtypes of HPV was introduced in England in 2008 for girls of school age. The incidence of cervical cancer is expected to reduce substantially in years to come and the impact of vaccination is already being observed in Scotland, where screening starts at an earlier age (20 years) than in England (25 years)¹²⁴. From September 2019, the vaccination programme has been extended to include boys and, as well as protecting men against a range of cancer, should further reduce the risk of cervical cancer in women in future years.

THE SCREENING PROCESS

Invitation

Women aged 25-49 years are invited every three years for cervical screening, with those aged 50-64 being invited every five years. Routine screening stops thereafter, unless a woman has had a positive result on one of her last three samples. In total, a woman should be invited 12 or 13 times in a lifetime.

The screen

The programme uses liquid based cytology to collect samples of cells from the cervix. The laboratory will examine these samples under the microscope to look for any abnormal changes in the cells.

Follow up

Women whose samples are negative for HPV will be recalled at the standard interval for their age group (3 or 5 years).

123 UK National Screening Committee, 2016. Screening in the UK: Making effective recommendations 2015 to 2016. Public Health England, [Online]. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733227/Screening_in_the_UK_making_effective_recommendations_2015_to_2016.pdf

124 BMJ 2019; 365:116 Palmer Tim, Wallace Lynn, Pollock Kevin G, Cuschieri Kate, Robertson Chris, Kavanagh Kim et al. Prevalence of cervical disease at age 20 after immunisation with bivalent HPV vaccine at age 12-13 in Scotland: retrospective population study

Those who are HPV positive and have normal cytology will be recalled for a further sample after one year.

Women who are HPV positive and have abnormal cytology and those who test positive for HPV twice running will be referred for colposcopy.

It is anticipated that referral for colposcopy will increase by around 25% in the next three years but will then fall back to current levels or lower.

Colposcopy for screen detected abnormalities is undertaken in the gynaecology services of NHS hospitals, alongside that for patients presenting with symptoms. It is a continuation of the cervical screening pathway, providing further evidence about the nature of observed changes. Colposcopy involves direct examination of the cervix through a magnifying lens and is usually undertaken in a clinic setting. There were nearly 176,000 referrals for colposcopy in 2017/18, of which around two thirds followed screening.

Some patients will require a biopsy or more extensive removal of abnormal looking cells. The latter may require a second visit. Biopsy samples are sent for histological examination which can show varying levels of abnormality, referred to as cervical intraepithelial neoplasia, which is graded as CIN1, CIN2 and CIN3. Rarely a patient may be found to have invasive cervical cancer.

CURRENT PERFORMANCE (AS AT 2017/18) ¹²⁵

A total of 4.46m screening invitations were issued, an increase of 0.3% on 2016/17. Nearly 20% of these were for women who had never previously attended for screening, with over two thirds being routine recalls. The remainder were women recalled because of previous abnormalities or inadequate samples.

Uptake for cervical screening is falling. A total of 3.18m (71.4%) women aged 25-64 were screened, an increase of 0.2% from 2016/17 but a decrease from 3.22m being screened in 2008. 17% of samples tested were not prompted by the screening programme but were 'opportunistic' samples taken when women presented to primary care.

Coverage is a measure of the percentage of eligible women who were screened within a specific timeframe (3.5 years for women aged 25 to 49 and 5.5. years for those aged 50-64. Unfortunately, this has fallen progressively over recent years in both age groups:

- Age-appropriate coverage (both age groups combined) fell from 75.7% in 2011 to 71.4% in 2017/18. Amongst 50-64 year olds the comparable figures were 80.1% and 76.2%, while those for 25-49 year olds were 73.7% and 69.1%.
- Coverage in 2017/18 varied between regions, with London at 64.7% and East Midlands at 74.5%. No local authority achieved 80% coverage, with 51 out of 150 having coverage below 70%.

¹²⁵ NHS Digital. 2018. Cervical screening programme 2017-18. [ONLINE] Available at: <https://files.digital.nhs.uk/B1/66FF72/nhs-cerv-scre-prog-eng-2017-18-report.pdf>

- Coverage is measured in a comparable way in Scotland, with performance there being 1.4% higher than in England.
- Amongst 25-64 year olds around 94% of samples were negative in 2017/18. 4.5% had borderline or low-grade abnormalities and 1.1% had high grade abnormalities.

The Cancer Reform Strategy (2007)¹²⁶ stated that all women should receive the results of cervical screening within 2 weeks (the 'turnaround time'). This was achieved in over 95% of cases in 2011/12 and 2012/13, but had fallen to 89.1% by 2015/16. Since then, there have been marked falls with only 58.6% receiving their results within two weeks in 2017/18:

- Dips in performance are repeatedly seen in February and March. This is widely thought to reflect GP practices encouraging screening before the financial year end, as screening numbers contribute to QOF points. In addition, cervical screening campaigns increasing the numbers of samples arriving in laboratories may contribute to the fall in performance at this time of year.
- Performance on turnaround times has fallen further over the past year or so, with performance in April 2017, 2018 and 2019 being 41%, 33% and 23.2% respectively, with wide variation at a regional and local level. This is attributable to workforce pressures resulting from the change to primary HPV screening. Cytoscreeners working in laboratories that will not be providing cervical cytology services have left to look for new work opportunities.

There were nearly 400,000 appointments in colposcopy clinics including new referrals, returns for treatment and follow ups. Of these, there were nearly 176,000 referrals, of which around two thirds followed screening and over one quarter followed clinical symptoms:

- In 2017/18, 99.5% of women with high grade abnormalities (high-grade dyskaryosis -moderate or severe) on screening were offered an appointment within four weeks from referral to first offered appointment. For all people requiring colposcopy, 40.6% were offered an appointment within 2 weeks and 98.5% within 8 weeks.
- 42% of women undergoing colposcopy following screening had no procedure, 45% had a biopsy and 13.5% had an excision or another procedure.
- The interval from biopsy to result was less than 2 weeks in 41% of cases and less than 4 weeks in over 85%. Almost all women received their results within 8 weeks.

126 Department of Health. 2007. Cancer Reform Strategy 2007. [ONLINE] Available at: <https://www.nhs.uk/NHSEngland/NSF/Documents/Cancer%20Reform%20Strategy.pdf>

STRENGTHS OF THE CERVICAL SCREENING PROGRAMME

The introduction of the screening programme has led to a marked reduction in incidence of cervical cancer, at a time when it would have been expected that incidence would increase due to changing patterns of sexual activity. It is important to note that while falling for people in older age groups, age-standardised incidence rates are, in fact, rising amongst 20-24 and 25-34 year-olds.

The effectiveness of the cervical screening programme is reflected in the falling numbers of new cases and deaths from cervical cancer over the past 30 years, though the recent increases at younger ages show that there are no grounds for complacency. In 2016, there were 2,594 new cases¹²⁷ in England and 682¹²⁸ deaths (UK-wide) from cervical cancer. It has been estimated that cervical screening saves around 5,000 lives each year¹²⁹.

OPPORTUNITIES

The following opportunities have been identified during the course of this review to further improve the uptake, coverage and functioning of the cervical screening programme:

- **Uptake and coverage** Coverage varies across the country and is at a 20-year low¹³⁰. It is particularly low in deprived populations and populations with high proportions of ethnic minority populations. Uptake is particularly low in women in the youngest age band (25-29 years). Evidence based interventions to increase uptake/coverage are not being systematically implemented in all parts of the country:
 - **Text reminders** A large-scale pilot in London has shown that it is possible to send text reminders to the large majority of women who are due for screening. This includes women who have never previously attended screening. Furthermore, this pilot resulted in an increase in uptake of over 4%¹³¹.
 - **Campaigns and use of social media.** Social media programmes, in some areas, have led to increases in uptake. These should be undertaken more widely with formal evaluation. If successful, these approaches should be adopted nationally. A peak in the number of women tested in 2009 can almost certainly be attributed to the widespread publicity following the

127 Cancer Research UK. 2019. Cervical cancer incidence by UK country. [ONLINE] Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/incidence#heading-Zero>. [Accessed 24 September 2019]

128 Cancer Research UK. 2019. Cervical cancer mortality by UK country. [ONLINE] Available at: <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/cervical-cancer/mortality#heading-Zero>. [Accessed 24 September 2019].

129 Peto, J. (2004). The cervical cancer epidemic that screening has prevented in the UK. *The Lancet*. 2004; Jul 17-23;364(9430):249-56. <https://www.ncbi.nlm.nih.gov/pubmed/15262102>

130 Albrow R, Kitchener H, Gupta N, Desai, M., 2012. Cervical screening in England: The past, present, and future. *Cancer Cytopathology*, [Online]. 120 (2), 87-96. Available at: <https://onlinelibrary.wiley.com/doi/full/10.1002/cncy.20203>

131 Kerrison RS, Shukla H, Cunningham D, Oyebo O, Friedman E, E., 2015. Text-message reminders increase uptake of routine breast screening appointments: a randomised controlled trial in a hard-to-reach population. *British Journal of Cancer*, [Online]. 10.1038, 1-6. Available at: <https://www.iplato.com/wp-content/uploads/2018/10/Breast-Cancer-Screening-Case-Study.pdf>

death of Jade Goody from cervical cancer. This was followed by a further peak in 2012 when the additional attenders would have been recalled. The additional peaks are only observed in the younger age group.

- **Acceptability of testing** HPV self-sampling may be more acceptable to some women than attending a GP surgery for sampling. This requires further evaluation.
- **IT systems** The cervical screening IT system is antiquated and subject to breakdowns/incidents. NHSX is now giving high priority to the development of new IT systems for screening programmes. Cervical cancer is recognised as being in the greatest need.
- **Managing the screening process** There have been several incidents of women either not being invited or not receiving results when they should have done. As a result, the contract with Primary Care Support England/ Capita has been ended and the work is being brought back within the NHS.
- **Transition to HPV** The changeover to primary HPV testing is proving challenging. Sample takers require additional training along with information for patients on which consent is based. Electronic links to laboratories and transport arrangements need to change as well as new processes and staffing arrangements within laboratories. This major service change has already led to a marked drop in turnaround performance. Mitigation arrangements are now being put in place, but performance may well continue to be poor throughout this financial year.
- **Intervals between screens** The HPV vaccination programme in girls and boys should lead to cervical cancer becoming very rare. It is likely that screening intervals will be able to be lengthened for women who have been vaccinated.
- **Trans and gender diverse people** Women who have transitioned to men may still have a cervix and thus be at risk of cervical cancer. If they are registered as males on IT systems, they may not be called for screening when they should be.

APPENDIX G: NHS DIABETIC EYE SCREENING PROGRAMME

THE NEED FOR SCREENING

Over 3.2 million people are registered with a GP as having diabetes and are thus known to the National Diabetes Audit. The number of people with diabetes is increasing by around 5% each year. People with diabetes are at elevated risk of blindness, related to retinopathy and maculopathy (changes at the back of the eye). However, if these diabetic eye problems are detected early, they can be successfully treated by laser or injection, thereby preventing blindness. Evidence shows that early identification and treatment of diabetic eye disease could reduce sight loss. The main treatment for diabetic retinopathy is laser surgery.

International comparison

In the middle-income countries of Europe, congenital cataract, glaucoma and, mainly, retinopathy of prematurity are highly expressed. The major cause of serious visual loss in adults in industrialised countries is age-related macular degeneration. The other conditions comprise cataract, glaucoma, diabetic retinopathy, and uncorrected/uncorrectable refractive errors, along with low vision. In people of working age, diabetic retinopathy, retinopathy pigmentosa, and optic atrophy are the most frequently reported causes of serious visual loss. Advanced cataract, glaucoma, and diabetic retinopathy are most frequently observed¹³².

Cataract remains the leading cause of visual impairment in all regions of the world in all age groups, except in the most developed countries. Other major causes of visual impairment are, in order of importance, glaucoma, age-related macular degeneration, diabetic retinopathy and trachoma¹³³.

THE SCREENING PROGRAMME

A diabetic eye screening (DES) programme was introduced in 2003 with the National Service Framework for Diabetes. The programme was hosted by Gloucester NHS Hospitals Trust until the formation of Public Health England (PHE). Since 2013, the service has been overseen by PHE, with commissioning being the responsibility of NHSE, as part of the Section 7A agreement.

132 Kocur I, Resnikoff S. Visual impairment and blindness in Europe and their prevention. *The British journal of ophthalmology*. 2002;86(7):716-22.

133 Resnikoff S, Pascolini D, Etya'ale D, Kocur I, Pararajasegaram R, Pokharel G, et al. Global data on visual impairment in the year 2002. *Bulletin - World Health Organisation*. 2004;82(11):844-51.

The DES programme requires all people with diabetes to be invited annually for screening. The eligible population for DES is all people with type 1 and type 2 diabetes aged 12 or over. People already under the care of an ophthalmology specialist for the condition are not invited for screening.

The service is seen as successful as diabetes is no longer the leading cause of blindness in working age people. In 2015, cataract was the most common cause for blindness, followed by age-related macular degeneration (AMD), glaucoma, uncorrected refractive error, diabetic retinopathy and cornea-related disorders, with declining burden from cataract and AMD over time¹³⁴.

Providers of services

As at April 2019, the service was provided by 58 service providers, which are a mix of NHS, independent and combined service providers. Each provider typically delivers the service in a range of locations including hospitals, GP surgeries, opticians and in a few cases vans and needs to serve a minimum of around 20,000 people with diabetes to be sustainable. This equates to a population of around 400,000. There is an optimum size of programme that depends on the area served but often works well on a county-wide level with referrals mostly into one ophthalmology department. There is no evidence of improvements in quality or efficiency by serving much larger populations. A summary of the programme is set out below:

THE SCREENING PROCESS

Identification

An automatic search of GP records is conducted monthly to ascertain people with diabetes who should be offered screening. The provider invites new patients for screening within three months by letter. The person with diabetes is offered an appointment. Once the individual has replied and has given a mobile number, text reminders are sent.

The screen

Digital images of the retina are taken by 'screeners' (typically Band 3/4). These are then assessed by 'graders' (Band 4/5). If positive, a second grader will review the image. If the two graders differ, the images are sent for arbitration. Each image takes 2-3 minutes to assess. Graders are tested on an external set of 20 image sets each month, and should complete at least 10 test sets/annum to maintain competence. Grading should be undertaken within two weeks of the image being taken.

134 Bourne RRA, Jonas JB, Bron AM, Cicinelli MV, Das A, Flaxman SR, et al. Prevalence and causes of vision loss in high-income countries and in Eastern and Central Europe in 2015: magnitude, temporal trends and projections. *The British journal of ophthalmology*. 2018;102(5):575-85.

Five 'pathways' are currently used depending on clinical circumstances. These are considered over complicated:

1. Routine
2. Digital surveillance (less than 1-year interval but variable)
3. Pregnancy
4. Slit lamp bio-microscopy (for people with ungradable images, of which the commonest cause is cataracts)
5. Treatment (hospital eye services)

Follow up

The screening programme offers 'digital surveillance' for people with non-urgent retinopathy/maculopathy from 1-12 monthly intervals. This prevents them being in hospital eye services.

People found to have moderate degrees of retinopathy, as defined by the grading criteria published by the DES Programme¹³⁵, are referred for further assessment, as are those with poor quality images. Women with diabetes who are pregnant are photographed more frequently as pregnancy is an independent risk factor for progression of retinopathy in this group.

Once a pregnant woman is identified by the programme (this can be from the GP practice or the women themselves contacting the programme) they are invited for additional screening. Others will be invited at intervals based on their screening history once extended screening intervals have been introduced for low risk groups. The normal interval currently being annually.

People with significant problems detected at screening are referred to their local NHS trust for further management. Urgent cases should be seen within 6 weeks. Less urgent cases within 13 weeks.

If significant retinopathy/maculopathy are detected the person is referred to the local NHS ophthalmology service. The two main treatments for retinopathy/maculopathy are laser and injection (Lucentis). These services are stretched with only 75.6% of urgent patients being assessed within set timeframes (against a KPI guidelines of 80%). KPI DE3 is an indicator of how quickly urgent patients are seen in hospital eye services. This KPI has not been achieved nationally for 3 years and is currently at 75.6% (acceptable is 80%).

Tariffs

Tariffs are in place for DES screening. In the South-West and South Central, a standardised tariff of £32.04 per screen is used but this is variable across the country.

¹³⁵ Gov.uk. 2012. Diabetic eye screening: retinal image grading criteria. [ONLINE] Available at: <https://www.gov.uk/government/publications/diabetic-eye-screening-retinal-image-grading-criteria>.

CURRENT PERFORMANCE (AS AT 2017/18)¹³⁶,

Uptake of screening is generally high (82.7% in 2017/18). Younger people (age 20-45) and socioeconomically deprived groups are less likely to attend.

One of the key performance indicators for DES is that participants should receive their results within three weeks. In 2017/18, this was achieved in over 94% of cases.

People with diabetes who are found to have proliferative retinopathy should be seen by a hospital eye service within six weeks. In 2017/18, this was achieved in 75.8% of cases against an acceptable standard of 80%. The overall standard has not been met for three years. Only 34 of 62 providers in 2017/18 met the acceptable standard, highlighting the need for close collaboration between DES and hospital eye services.

NHS Diabetic Eye Screening Programme (2017/18)	
Eligible people with diabetes known to programme	3,297,294
Offered screening (routine digital screening)	2,700,774
Tested (routine digital screening)	2,232,797
Uptake	82.7%
New registrations to programmes	274,211
Urgent referrals (R3A)	8,782
Routine referrals (R3SM1, R2M1, R2M0, R1M1)	54,893

R1 = Background retinopathy;
R2 = Pre-proliferative retinopathy;
R3A = Active proliferative retinopathy;
R3S = stable treated proliferative retinopathy;
M0 = No maculopathy;
M1 = Maculopathy.

STRENGTHS

Uptake of screening is generally high as set out above. The extraction tool, GP2DRS, also works well – searching for people coded as having diabetes and for other information such as prescriptions of insulin or oral medication. This information is then linked to the local service provider.

Some services employ unpaid champions to increase uptake by working with community groups (e.g. local church communities).

¹³⁶ Gov.uk. 2015. NHS screening programmes: annual report. [ONLINE] Available at: <https://www.gov.uk/government/publications/nhs-screening-programmes-annual-report>.

OPPORTUNITIES

The following opportunities have been identified during the course of this review to further improve the uptake, coverage and functioning of the DES screening programme:

- **Interval between screens** The UK NSC has recommended that the screening interval can be extended to two years for those with no evidence of retinopathy. However, this is being held up by the difficulties in upgrading IT and complexities of local commissioning of services. National modelling of changes to services would be beneficial.
- **Data extraction** GP2DRS does not extract some information which would be useful, such as HbA1C and blood pressure, both of which are indicators of risk of retinopathy. Scotland does extract comparable information. If information on these factors were to be available it is possible that screening could be risk stratified.
- **IT systems** If an individual moves screening programmes due to moving out of area there is no cross functionality across IT systems to allow their previous screening record to be transferred with them, this leads to additional screening episodes for these individuals. There is an urgent need for a single IT system to be used by all providers. Further detail is set out in Appendix H.

Other opportunities include:

- Improved links between service providers and hospitals.
- Artificial intelligence has the potential to support grading in the future, and help to offset pressure on the workforce through growing numbers of people with diabetes.
- Introduce optical coherence tomography (OCT) into the programme to improve the capacity in hospital eye services.
- Link information on DES with other metrics for control of diabetes.

APPENDIX H: CURRENT IT SYSTEMS SUPPORTING NHS SCREENING IN ENGLAND

AAA (commissioned by Public Health England)

Identification/managing screening: NHS Digital, using NHAIS, supply data on the eligible population for screening to the IT system provider (Northgate). The IT provider sends relevant data to each AAA provider who issue the invitations. There are active plans to move the core data from NHAIS to PDS (the 'spine') and a number of implementation issues are currently being addressed.

Recording results: Done by individual AAA providers using the central system provided by Northgate.

Challenges: Good links have been established with the vascular surgery registry. However, linkage with GP systems and with data from NHS trusts is suboptimal.

Bowel (commissioned by Public Health England)

Identification/managing screening: NHS Digital run a single Bowel Cancer Screening System for England which maintains organisation-related information; manages lists of people eligible for screening; sends invitations, manages appointments; sends out test kits; records results and provides operational reports (See: <https://digital.nhs.uk/services/screening-services/bowel-cancer-screening-services>).

Recording results: As above (end-to-end system).

Challenges: While this is a single system covering the full pathway with automated call and recall, challenges remain around migration from NHAIS to Spine.

Breast (commissioned by Public Health England)

Identification / managing results: Breast screening services in the UK are supported by NHS Digital who provide the software to manage the call and recall of women who are eligible for breast screening. See: <https://digital.nhs.uk/services/screening-services/breast-screening-services>

Recording results: A private provider (Hitachi) provides the National Breast Screening System (NBSS) which is used to record the outcomes of breast screening appointments and a woman's screening history.

Challenges: 79 providers have a locally hosted copy of the database (BSS) which is divergent from NBSS. These rely on NHAIS to provide demographic info in batches (screening history etc.). There is limited interoperability between NHAIS and BSS/NBSS. Hospital scans need to be manually inputted.

Cervical (commissioned by NHS England)

Identification / managing results: On 1 September 2015, Capita plc. took on responsibility for delivering NHS England's primary care support service – now called Primary Care Support England (PCSE) – including delivery of the 'call and recall' service for cervical screening (<https://pcse.england.nhs.uk/services/cervical-screening/>). It was announced in March 2019 that NHS England would bring delivery of the call and recall service back in-house, beginning in June and with a phased transition through the rest of the year.

Recording results: Currently supported by NHS Digital (via NHAIS) until its replacement as part of the Primary Care Services Transformation Programme.

Challenges: Data resides in over 500 instances of over 60 systems supplied by over 60 suppliers with data exchange between them being predominantly paper based resulting in clinical risk, poor data quality and difficult access.

Diabetic Eye Screening (DES) (commissioned by local diabetic eye services, with PHE nationally advising on service specification)

Identification / managing screening: Local DES providers use GP2DRS to extract details from GP records on which patients have diabetes (T1 or T2).

Recording results: Entered on relevant systems across 58 local providers.

Challenges: PHE develop the overall software specification requirements for software suppliers, with contracts held locally. Most local DES services use one of two national software suppliers, with a small number using local systems. Each service provider has its own version of the IT system, so there are in effect 58 systems, these are now generally standardised so that everyone should be on the same version. They do, however, record episodes slightly differently and so comparing programmes with different systems can be difficult. Comparisons of data held on different IT systems are considered to be potentially unreliable.

Some contracts are held separately, whilst others are rolled up with an overall service contract. Any changes to IT systems have to be made individually for each of the service providers and incurs a cost. These fragmented arrangements hinder wider change (e.g. introducing reduced screening intervals for low risk patients which relies on up-to-date data). Local service providers have developed multiple workarounds. For example, there is no software to meet the needs of women who are pregnant, despite NICE having issued guidance on how these patients should be managed. The IT systems do not allow for non-binary people who do not wish to be addressed with their pronoun assigned at birth'.

