



Public Health
England



Supporting the health system to reduce inequalities in screening PHE Screening inequalities strategy

Public Health England leads the NHS Screening Programmes

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-leading science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health and Social Care, and a distinct delivery organisation with operational autonomy. We provide government, local government, the NHS, Parliament, industry and the public with evidence-based professional, scientific and delivery expertise and support.

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About PHE screening

Screening identifies apparently healthy people who may be at increased risk of a disease or condition, enabling earlier treatment or better informed decisions. National population screening programmes are implemented in the NHS on the advice of the UK National Screening Committee (UK NSC), which makes independent, evidence-based recommendations to ministers in the four UK countries. The Screening Quality Assurance Service ensures programmes are safe and effective by checking that national standards are met. PHE leads the NHS Screening Programmes and hosts the UK NSC secretariat.

www.gov.uk/topic/population-screening-programmes

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Contents

About Public Health England	2
About PHE screening	2
Foreword	4
Introduction	6
Background	9
Screening inequalities and the case for action	10
Vision, aim and objectives	16
Current and planned activities	17
Monitoring progress	20
Governance	20
Appendix A	21

Foreword

1.1 Our world leading national screening programmes save lives, improve health and enable choice. Every year across the UK approximately:

- 5,000 deaths are prevented by cervical screeningⁱ
- 2,400 bowel cancer deaths are avoided screeningⁱⁱ
- breast screening prevents 1,300 women dying of breast cancer every yearⁱⁱⁱ
- 7,000 people with sight threatening diabetic retinopathy are referred to hospital eye services for urgent treatment^{iv}
- 2,500 men have a potentially life threatening aneurysm detected^v
- 1,000 babies, who may otherwise have been born with HIV are born free of the condition^{vi}
- 1,100 babies with hearing problems are helped to reach full educational and social potential through early diagnosis and treatment^{vii}

In addition, 24,000 fewer invasive tests were carried out over the last 10 years due to improved Down's syndrome screening. These tests carry a small risk of miscarriage.

1.2 National screening programmes are population based, meaning that a test is offered to everyone in a defined population group (for example all women aged 50 to 70 or every newborn baby). Many of the conditions for which we offer screening and treatment disproportionately affect individuals from socio-economically deprived backgrounds or those with the **9 protected characteristics** as described in the **2010 Equality Act**. National screening programmes therefore have an important role to play in reducing health inequalities.

1.3 Variation in participation exists both within and between national screening programmes and generally, people at higher risk of the condition being screened are less likely to participate.

1.4 In September 2015, Public Health England (PHE) Screening held a stakeholder workshop on **inequalities in screening**. The workshop demonstrated huge enthusiasm for addressing inequalities in screening. It identified a number of actions, and more significantly, it proposed that these should be developed into an overarching strategy to address what work PHE Screening could take forward to support local partners (including NHS England, local authorities, Clinical Commissioning Groups (CCGs), primary care, providers and the third sector to reduce inequalities in screening.

1.5 Work to address inequalities in screening is progressing both locally and nationally but there is still more to be done to overcome the challenges we face. It is essential that we continue to explore how screening can be more effective at reaching those in greatest need. The time is right to bring this work together into a

cohesive and coordinated strategy to reduce screening inequalities and make sure there is informed personal choice and equitable access for all.

Introduction

- 2.1 PHE exists to protect and improve the public's health and wellbeing and reduce health inequalities. We do this through world-class science, advocacy, partnership, education, knowledge and intelligence, and the delivery of specialist public health services.
- 2.2 **PHE Screening** works to support those responsible for the commissioning and local delivery of national screening programmes. This work includes a joint effort to promote equitable access to screening services.
- 2.3 All parties responsible for the delivery of screening have legal duties in relation to health inequalities.

The health inequalities duty (Health and Social Care Act 2012)

The **Health and Social Care Act 2012** introduced specific legal duties on health inequalities for the Secretary of State for Health which PHE must meet on his behalf. The duty requires public authorities to have due regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service. It applies to all PHE public health functions, not just healthcare focused work.

The public sector equality duty (Equality Act 2010)

The **equality duty** is a responsibility on public bodies and others carrying out public functions which ensures that they consider the needs of all individuals in their day-to-day work in shaping policy and delivering services, and in relation to their own employees. In the exercise of their functions, public bodies have a general duty to have due regard to the need to:

- eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act
- advance equality of opportunity between people who share a protected characteristic and those who do not
- foster good relations between people who share a protected characteristic and those who do not

The Public Services (Social Value) Act 2013

This **Act** requires people who commission public services to think about how they can also secure wider social, economic and environmental benefits.

The Accessible Information Standard

This **standard** ensures that people with a disability, impairment or sensory loss are given information in a way they can access and understand and any communication support that they need.

- 2.4 The strategy has been developed to support PHE Screening in discharging its professional and legal commitment to reduce inequalities, ensure equitable access to screening and to support its partners involved in the delivery of screening. This strategy is consistent with the **PHE equality objectives: 2017 to 2020** and PHE's **Strategic Plan**.
- 2.5 PHE produces **evidence, resources and guidance** to help support national, regional and local areas to reduce health inequalities.
- 2.6 The commissioning and delivery arrangements for screening, set out in the **Immunisation and Screening National Delivery Framework and Local Operating Model** mean that public health system leadership is required to tackle screening inequalities by establishing effective partnerships with local communities, third sector organisations commissioners, providers, local authorities.
- 2.7 In the future, 'sustainability and transformation partnerships' (STPs) and emerging accountable care systems/organisations are expected to shape further the commissioning and service delivery landscape.
- 2.8 This strategy seeks to address the unwarranted and unfair barriers that may mean people do not engage with an offer of, or participate in, screening or who are disadvantaged in maximising the benefits of screening. Examples of barriers to screening include physical and communication barriers as well as cultural and social barriers.
- 2.9 Informed personal choice is central to the screening strategy. The decision to have a screening test or not is for the individual involved. The decision will be consistent with the values of the individual and their unique circumstances and should be free from pressure.
- 2.10 However, many people choose not to take a decision about screening, are not aware of the offer or simply do not attend their appointment or complete the self-test. There is therefore an opportunity for stakeholders to engage further with this group of people. This engagement might include targeted community awareness initiatives perhaps with community groups or faith leaders as well as the provision of individual support and advice. It will also require services to address any barriers they might present.
- 2.11 We must also recognise that there will always be some degree of variation between different groups in their acceptance of a national screening programme.

2.12 The strategy's development has been overseen by a Strategy Oversight Group, made up of a range of stakeholders including NHS England, PHE, local authorities and the third sector (see Appendix A).

Background

- 3.1 Screening is a way of identifying apparently healthy people who may have an increased risk of a particular condition with the aim of providing treatment to prevent the disease or illness arising from it.
- 3.2 The NHS screening programmes currently offered in England are listed below. These screening programmes save lives, reduce illness and disability and promote choice:
- NHS abdominal aortic aneurysm (AAA) programme
 - NHS bowel cancer screening (BCSP) programme
 - NHS breast screening (BSP) programme
 - NHS cervical screening (CSP) programme
 - NHS diabetic eye screening (DES) programme
 - NHS fetal anomaly screening programme (FASP)
 - NHS infectious diseases in pregnancy screening (IDPS) programme
 - NHS newborn and infant physical examination (NIPE) screening programme
 - NHS newborn blood spot (NBS) screening programme
 - NHS newborn hearing screening programme (NHSP)
 - NHS sickle cell and thalassaemia (SCT) screening programme
- 3.3 The aims of screening programmes:
- **Pregnant women** - offer women and their families screening tests to learn the likelihood that they or their baby has a higher chance of a specific health problem or congenital condition and, where appropriate, to receive early treatment and/or to support the process of making an informed decision
 - **Newborn** - offer parents screening tests to identify certain medical conditions, or increased risk of conditions in their baby before symptoms occur so that their baby can be offered an intervention or treatment which can reduce morbidity and mortality
 - **Young people and adults** - PHE Screening produces information and training packages to support individuals make personal choice and guide professionals in facilitating informed personal screening choices.
- 3.4 Screening is a pathway not just a test, having offered a test, health care providers have an obligation to make sure that the individual is cared for throughout their screening journey.
- 3.5 All national screening programmes participate in regular quality assurance activities as led by the **Screening Quality Assurance Service (SQAS)**, to drive continuous service improvement.

Screening inequalities and the case for action

4.1 Health inequalities are systematic, avoidable and unjust differences in health and wellbeing between different groups of people^{viii}. These differences arise from the wider social determinants of health as illustrated in Dahlgren and Whitehead's model depicting the wider determinants of health.



The Determinants of Health (1992) Dahlgren and Whitehead

4.2 The Marmot review *Fair Society, Healthy Lives* (2010), a strategic review of health inequalities in England, highlights the social gradient of health inequalities from which the more disadvantaged the person's social position, the worse their health. The review highlights the need for universal action that increases in scale and intensity in proportion to the level of disadvantage.

4.3 Health inequalities arise from:

- **structural issues** – the fundamental 'causes of the causes' are differences in experiences of the wider determinants of health between groups, for example, income, employment, education and housing, which influence people's position in society

- **unhealthy behaviours and other individual risks** – we know that health behaviours are not equally distributed across the population and this difference contributes to inequalities in premature death
- **inequitable access to or experience of services** – which can be a result of discrimination due to inaccessible services, public information or healthcare sites that is relevant pertinent to their particular needs, for example, services that fail to make a reasonable adjustments required by the Equality Act 2010

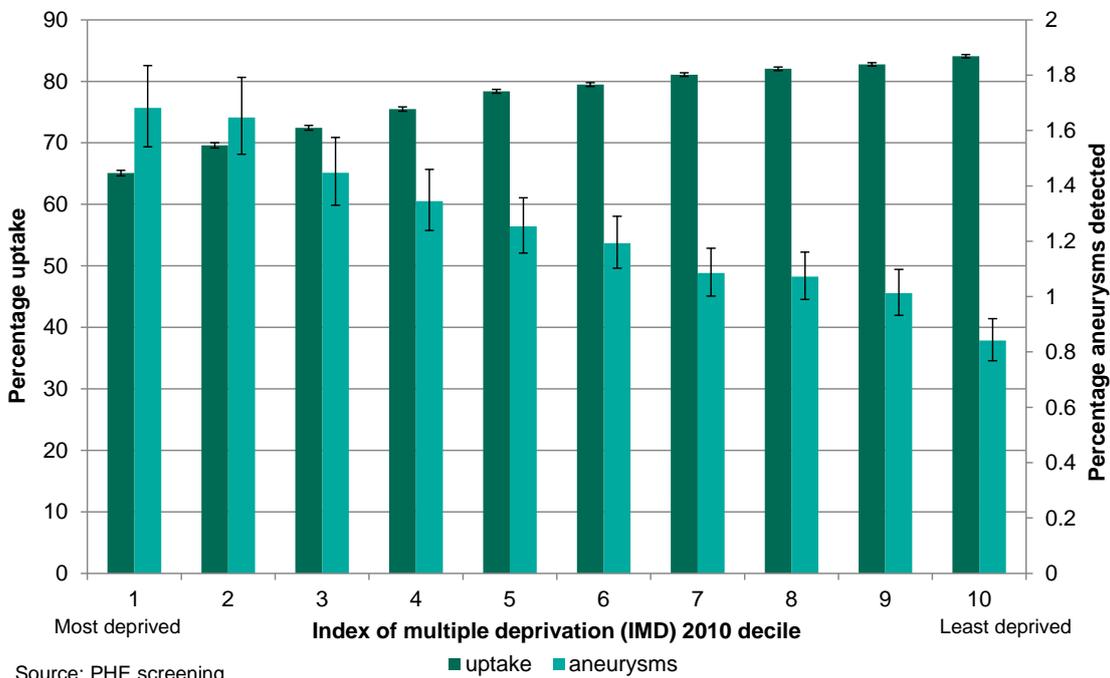
- 4.4 Health inequalities in England exist across a range of dimensions or characteristics and include some of the 9 protected characteristics of the Equality Act 2010, socio-economic position and geography.
- 4.5 These dimensions include those who are not registered with a GP, homeless people and rough sleepers, asylum seekers, gypsy and traveller groups, sex workers, those in prison, those experiencing severe and enduring mental health problems, those with drug or alcohol harm issues and those with communication difficulties.
- 4.6 Screening stakeholders are limited in their ability to influence the structural causes of health inequalities but do have scope to address inequitable access to or experience of screening.
- 4.7 Screening inequalities can manifest themselves at any point along the screening pathway. The pathway consists of:
- cohort identification (invitation)
 - provision of Information about screening
 - access to screening services
 - access to treatment
 - onward referral
 - outcomes
- 4.8 The inequalities may be at:
- national programme level
 - regional level
 - local programme level
 - small geography (for example, local authority, hospital catchment or GP) level
- 4.9 Barriers that persist once a person has commenced screening pathway may result in some people being unable to maximise the benefits of screening. For example if a person has a higher chance result but they don't then get the follow on treatments then they won't reduce their risk.
- 4.10 We know these inequalities in screening exist. However, we do not know the full extent of inequalities within all of our screening programmes because:

- we do not currently collect the relevant data
- data may be collected on IT systems but not easily accessible to us
- there is a lack of evidence on the reasons for the inequality and how we can effectively tackle the issues

4.11 The actions we take need to provide us with the information necessary to reduce the impact of inequalities in screening.

4.12 Examples of inequalities in screening include:

Within the NHS AAA screening programme those people experiencing social deprivation, are less likely to attend and participate in screening and the proportion of aneurysms detected is inversely correlated with increasing deprivation.



People in more deprived groups are less likely to complete bowel screening (35% for the most deprived group compared to 61% for the least deprived)^{ix} and are more likely to die from bowel cancer^x.

Women in the most deprived groups (most deprived quintile) are less likely to attend cervical screening (odds ratio (OR) 0.91 to 0.94 when compared to the least deprived quintile^{xi}) yet are more likely to have high risk HPV, and a higher risk of being diagnosed with/dying from cervical cancer^{xii}.

Women in the most deprived groups are generally less likely to participate in breast screening (relative risk (RR) 0.89 for the most deprived groups compared to the least deprived)^{xiii} but are more likely to die from breast cancer^{xiv}.

Uptake of bowel screening in England is lower in the ethnically diverse areas (38% compared to 52 to 58% in other areas)^{xv}.

Women from ethnic minority groups are less likely to attend cervical screening compared to White British women (OR 2.20 for White British women compared to ethnic minority women)^{xvi}. The disparity is particularly great for certain ethnic minority groups – for example the likelihood of non-attendance reaches OR 10.69 and OR 12.86 for Indian and Bangladeshi women respectively compared to White British women^{xvii}.

There is some evidence that women from ethnic minority groups are less likely to attend breast screening compared to White British women, but estimates vary by study and by minority ethnic group^{xviii}.

People from South Asian communities are known to be up to 6 times more likely to have type 2 diabetes than the general population. In addition, this population group tend to have poorer diabetes management, putting them at higher risk of serious health complications including diabetic retinopathy. Data analysed from the Clinical Practice Research Datalink (CPRD) showed the prevalence of diabetic retinopathy to be highest in the South Asian population and also in the most deprived geographical group^{xix}.

In cervical screening uptake is markedly higher among 50 to 64 year olds than among 25 to 49 year olds^{xx}.

Women with disabilities are less likely to participate in breast screening (RR 0.64 compared to those without disabilities). This is particularly the case for those with disabilities relating to self-care or vision, or for those with 3 or more disabilities^{xxi}. Women with learning disabilities are also less likely to participate in breast screening (incident rate ratio (IRR) 0.76 compared to those without learning disabilities)^{xxii}.

Women reporting any disability are less likely to participate in bowel screening (RR 0.75 compared to those without disabilities). This is particularly the case for those with disabilities relating to self-care or vision, or for those with 3 or more disabilities^{xxiii}. People with learning disabilities are also less likely to participate in bowel screening (IRR 0.86 compared to those without learning disabilities)^{xxiv}.

Women with learning disabilities are less likely to participate in cervical screening (IRR 0.54 compared to those without learning disabilities)^{xxv}.

Men have a lower uptake of bowel screening (51% compared to 56% for women)^{xxvi} but are more likely to be diagnosed and die from bowel cancer (male:female ratio 12:10)^{xxvii}.

Overall, there is limited published evidence on inequalities in antenatal and newborn screening programmes. However, 2013 UK research using large

survey data consolidated evidence that single women, those from ethnic minorities and younger women are more likely to make late bookings for antenatal care, have fewer antenatal checks and engage less with screening^{xxviii}.

In NHS London an equity audit undertaken in 2015/16 found:

- evidence of inequalities in access to timely antenatal care across London
- many of the characteristics of women at greater risk of booking at more than 10 weeks gestation were also associated with social disadvantage, poorer pregnancy outcomes and poorer infant health
- there was considerably longer wait from referral to booking for women living in higher deprivation areas
- for several maternal characteristics (including first language other than English, Jewish religion, unemployment and most black and minority ethnicities), a later referral is compounded by a longer wait from referral to booking

4.13 However, even when people who experience health inequalities attend for screening the **system and process** may disadvantage them from maximising the benefits of screening.

4.14 Reducing health inequalities in screening can bring significant savings to both the individual and the NHS. For example:

- We know that patients diagnosed with bowel cancer through screening and elective routes have **higher survival rates** compared with patients diagnosed through emergency presentations.
- For cervical cancer screening, the later the diagnosis, the more invasive the treatment options and the poorer the health outcomes. Long term modelling by Jo's cervical cancer trust has found "incidence of cervical cancer is set to increase substantially in older women if current coverage of cervical screening remains the same. By 2040 incidence will increase by 16% among 60 to 64 year olds and 85% among 70 to 74 year olds^{xxix}.
- The NHS CSP **cervical cancer audit** 2007 to 2010 found 56% of women aged 50 to 64 with fully invasive cancer hadn't been screened within 7 years, compared to only 16% of women without cervical cancer.

4.15 We can do more to support individuals make an informed personal choice about whether or not to accept the offer of screening. However, behavioural change theory shows how complex this process can be. Community, cultural and economic factors all have an influence on the choices individuals make, as does access to screening services which are often worse in areas with the greatest need.

4.16 Strengthening efforts to understand and engage with specific community groups can help to address variations in participation. Jo's cervical cancer trust's **Cervical**

screening in the spotlight contains examples of campaigns or activities to target specific groups of women who had not engaged with screening.

4.17 There are significant challenges to be addressed in reducing screening inequalities, for example:

- training, recruitment and retention of specialist screening staff
- limited capacity within screening and immunisation teams and in the wider public health system
- the collection of core demographic data is compromised by deficiencies in some screening and national IT systems which can make assessing and evaluation effectiveness of service innovation harder
- limited resources for monitoring and the complex evaluation of screening inequalities
- the lack of timely access to data to enable monitor the impact of interventions

Vision, aim and objectives

- 5.1 Our **vision** is that all screening services can be accessed by all communities and that everyone, regardless of their social and personal circumstance, has an opportunity to make an informed personal choice about screening.
- 5.2 Our **aim** is to maximise the health outcomes of national screening programmes and reduce health inequalities.
- 5.3 Our **objectives** are to:
- provide leadership and strategic direction to tackle inequalities in screening
 - provide those responsible for the delivery and commissioning of screening services with the evidence and tools they need

The evidence and tools will:

- identify screening inequalities
- ensure pathways are designed that take account of the needs of people less likely to engage in screening
- engage with local communities and eligible screening groups, to understand barriers to screening

This will happen by:

- focusing on interventions which can have greatest impact
- making evidence-based contributions to policy debate and to the wider system that support reductions in health inequalities
- influencing government and our partners to raise the profile of inequalities in screening
- empowering local action – recognising and supporting best practice, building innovation and facilitating sharing
- working collaboratively with local authorities and other partner organisations responsible for place based community engagement
- using research to identify and address barriers that prevent people and communities from engaging with or participating in screening
- supporting informed personal choices with the provision of accessible, fit for purpose information and education for the public and health care staff

Current and planned activities

6.1 This section provides a brief summary of our recent actions to tackle inequalities in screening.

Following recommendation by the UK National Screening Committee, PHE Screening has been working with partners to accelerate replacement of the current guaiac faecal occult blood test (gFOBt) with the faecal immunochemical test (FIT) in the bowel screening programme. We hope to introduce this new test in 2018/19. A pilot of FIT in 2014 showed a marked impact on uptake, with a 7% increase overall, equivalent to an additional 290,000 participants per annum. It increased uptake in groups with low participation rates such as men, ethnic minority populations and people in more deprived areas^{xxx}.

PHE Screening has commissioned a group to guide research into using FIT and additional risk factors to improve the accuracy of the screening test.

These indicators will include delayed or infrequent participation which are particularly associated with deprivation and ethnic minority groups. When combined with FIT these markers improve the detection of cancer and adenomas.

A PHE Screening Data Group is developing information about the availability of core screening data (Key Performance Indicators and standards) against the protected characteristics. This will support national and local research in relation to inequalities and public health initiative planning.

PHE Screening's NHS CSP team has worked in partnership with NHS Digital and Jo's cervical cancer trust to produce an **electronic data package**. The package will support GP practices and CCGs to look at local screening access and coverage rates.

PHE Screening's NHS AAA screening programme is developing an inequalities toolkit which will give local providers clear data, enabling them to identify areas of inequality in their local area(s), produce guidance to enable local providers to use data to reduce inequalities and increase coverage within their local area(s). The toolkit will also share examples of good practice.

PHE Screening has a Memorandum of Understanding (MoU) to allow **sharing of data with NHS England and public health commissioning teams**. This MOU also enables NHS England to share data with other delivery partners including the Local Authority Directors of Public Health.

PHE Screening commissioned a rapid review of interventions to improve participation in cancer screening services.

Where we have good quality evidence PHE Screening uses this information to inform revisions to national screening service specifications **2017 to 2018 service specifications**

For example, service specifications for cancer screening now include references to text messaging, timed appointments, reminder letters and GP endorsed appointment letters.

We know there is a great breadth of activity taking place across England to reduce inequalities in screening programmes. PHE Screening has introduced a mechanism to **share good practice**. This provides an opportunity to share innovative work to reduce inequalities with delivery partners.

PHE Screening and/or NHS England commission and or provide IT systems to support screening programmes. These are variable in quality and how much of the pathway they cover. PHE Screening will, where possible, work to include protected characteristics into all screening data sets. PHE Screening will also work with suppliers and NHS England to include the ability to support a choice of alternative communication types (SMS messaging, email).

The NHS BSP and BCSP IT services have an additional care needs flag. Where GP practices have obtained consent from their patients to share information about additional care needs this enables the programme to notify, for example, learning disability teams of imminent invitations to take part in screening. A project is being taken forward to enable this additional care needs flag to be populated directly from a spine data feed which in turn will be populated by GPs.

PHE Screening will share learning on inequalities and share best practice through our **PHE Screening blog**.

National screening programmes have defined **standards** and guidance to ensure that services are safe, effective and of a high quality. These are reviewed on a regular basis to drive improvement and understand the impact of standards on inequalities. Each programme has either coverage and/or uptake standards to monitor and maximise uptake of screening in the eligible population who chose to accept screening. In addition to this some screening programmes have developed standards to focus on specific areas that are or may be linked to inequalities, for example diabetic eye screening has a standard to help identify patients who regularly miss screening appointments and sickle cell and thalassaemia screening have developed a standard on timeliness of offer or pre-natal diagnosis.

A PHE Screening standards subgroup has been established and part of the group's work is to explore and develop new standards to help monitor inequalities.

PHE Screening has produced high quality information to support informed choice in screening. All information meets the Accessible Information Standard. We provide screening information in English and 12 other languages. A leaflet for trans (transgender) and non-binary people in England has been produced to explain the adult NHS screening programmes that are available in England and

explains who we invite for screening. We are developing **easy read leaflets** across all screening programmes in multiple languages.

PHE has developed e-learning modules on health equity. PHE Screening is undertaking an in house public health skills audit to make best use of existing expertise, share learning and target training. All PHE Screening staff can access PHE's Health Equity Assessment Tool (HEAT) to inform all major programmes of work and support them to systematically assess health inequalities.

PHE Screening works with its partners, including:

- colleagues within PHE leading on learning disabilities to take forward work to **improve access to screening** for people with these conditions
- the PHE health and justice team to develop a pathway to ensure all people in prison are offered screening for bowel cancer, abdominal aortic aneurysm and diabetic eye screening
- colleagues in NHS England to measure and improve NHS performance, by sharing data, providing clear evidence based service specifications. We contribute to and follow up on actions from NHS England spotlight sessions on falling uptake in breast cancer and cervical screening
- the third sector, for example, supporting Jo's Cervical Cancer Trust in their launch of **Be Cervix Savvy Roadshows**

The operating model for the screening quality assurance service (SQAS)

2018/19 to 2020/21 has identified a goal to contribute to the reduction of health inequalities across screening programmes. This will be measured by improvement trends identified from quality assurance visit reports and action plans. To support this goal SQAS will take forward a QA inequalities plan of work that will ensure staff have access to the necessary tools, resources and training to enable the systematic and effective QA service actions to reduce screening inequalities.

- 6.2 PHE Screening will build on these actions and continue to support those in the health system with responsibility for the delivery of screening programmes. These actions will be designed to meet the overarching objectives set out in this document.
- 6.3 PHE Screening will continue to share and update these actions through established communications channels, for example blogs.

Monitoring progress

- 7.1 PHE Screening will use a number of different mechanisms to engage with stakeholders, evaluate the strategy and demonstrate progress. This will include:
- the use of blogs to allow for ongoing stakeholder updates, input and feedback
 - Identification or development of measurable indicators focusing on tackling health inequalities
 - collecting, collating and reporting on information gathered through formal and informal QA team contacts and visits
- 7.2 We will seek views on the strategy and its usefulness more formally in a year's time.

Governance

- 8.1 Equality is an objective for PHE Screening and the actions will be monitored and reported through PHE Screening, health improvement and PHE corporate scorecards.

Appendix A

Members of the Strategy Oversight Group

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