

Cancer Research UK's response to Sir Mike Richards review of national cancer screening programmes in England

Cancer Research UK welcomes the opportunity to respond to the review of the national cancer screening programmes. Screening can detect cancers at an early stage and in some cases can prevent cancers from developing in the first place. Around 5 in 100 cancer cases in England are diagnosed by screeningⁱ and of these, around 9 in 10 of these cases with are diagnosed at an early stage (stage I or II)ⁱⁱ. Despite these benefits, screening does present potential harms. The tests used in cancer screening can miss cancers and diagnose cancers that would have never gone on to harm the individual.

The NHS Long Term Plan sets an ambition for 75% of all cancers to be diagnosed at stage I or II by 2028 – an increase of 21%. Screening will play an important role in the delivery of these ambitions: Cancer Research UK estimates that improvements to cancer screening programmes, including bowel screening optimisation, the introduction targeted lung screening, and further optimisation of existing programmes, could contribute 4% of the required stage shiftⁱⁱⁱ. It is therefore crucial that screening programmes are fit for the future and yield optimal population benefit in the most effective and efficient ways to help prevent cancers from developing and reduce late-stage associated mortality.

In 2017/18 around 11,480,000 screening invitations were sent as part of the national screening programmes in England^{iv}. The scale of the programmes is significant - and it must maximise informed uptake by removing barriers to access so every eligible person who wants to be screened can access the programme with ease.

Cancer Research UK is a partner in the delivery of aspects of UK cancer screening programmes and this response is informed by that experience. Our policy on screening programmes is also informed by extensive input from clinicians and researchers and from those offered to take part in screening.

Key points

- Currently there is no organisation solely responsible for delivering cancer screening in England, creating confusion about roles and responsibilities. The Department of Health and Social Care, working with arm's length bodies, must provide clarity on organisational accountability for delivering cancer screening programmes. This should include clarity on accountability for:
 - the everyday delivery of cancer screening programmes
 - delivering improvements to existing programmes such as reducing barriers to access
- NHS England should be clearly accountable for introducing major changes to existing programmes such as the implementation of new test and ensure changes to cancer screening programmes are implemented effectively and on time, ensuring that the whole system is capable of implementation.
- The Government must clarify the role of the UK National Screening Committee in approving and quality assuring new risk stratified approaches to screening.
- The Department of Health and Social Care must invest in the IT infrastructure which delivers cancer screening programmes to ensure equity of access to take part in screening, help reduce health inequalities and robust data collection.

- Public Health England, working with partners, should continue to work towards increasing informed uptake of screening with a focus on reducing inequalities.
- NHS England, NHS Improvement and Health Education England should consider the workforce requirements of national screening programmes in the forthcoming Workforce Implementation Plan. Increasing workforce capacity in screening and diagnostic services is fundamental to optimising the current national cancer screening programmes and will be required for swift implementation for future screening programmes.
- Careful consideration must also be given to how artificial intelligence can assist clinicians as well as how services are commissioned and funded.
- We would like to see research integrated as a core pillar of a programme, allowing for research to be conducted and evaluated in parallel to the programme, rather than independently, as well as increased access to screening data for researchers.

Greater clarity is needed on the governance of the Cancer Screening Programmes

Currently there is no organisation solely responsible for delivering cancer screening in England. Within the Section 7A agreement of the NHS Act 2006, several different organisations are responsible for different aspects of delivery. This agreement is based on a shared commitment, and requirement, to partnership working between the Department of Health and Social Care (DHSC), NHS England (NHSE) and Public Health England (PHE), to protect and improve the public's health.

NHS England is responsible for directly commissioning and funding high quality cancer screening programmes set out under the agreement between DHSC and NHSE. With efficient use of the finite Section 7A resources, NHSE must seek to achieve positive health outcomes and reduce health inequalities. NHSE is responsible for implementing planned changes in services in a safe and sustainable manner, promptly and thoroughly.

PHE is responsible for delivery of the essential elements of screening programmes which are best done once at national level - including the procurement of screening equipment and IT where appropriate. PHE is also responsible for developing and providing accessible information to both the public and healthcare professionals. It is also responsible for the delivery of national quality assurance and for ensuring training and education for all those providing screening is developed, commissioned and delivered through appropriate partner organisations.

The governance of the cancer screening programmes must be clearer and have greater transparency on who is responsible for driving forward the changes in a screening programme when it involves several different organisations. PHE are responsible for the procurement of new screening tests but the procurement of FIT had to be done through a bowel screening hub as the contract with the supplier is held by NHS England. We also understand the commitment from PHE to lower the screening age to 50, something NHSE was unaware was being announced, nearly jeopardised the second attempt at procuring FIT. Greater communication between the different organisations involved is needed to deliver any changes to the cancer screening programmes in a safe and timely manner. It may be beneficial to identify a person who has oversight of all aspects of the changes required, regardless of the organisation responsible, and is responsible for managing the timings of these changes.

We would like to see swift adoption of new technology in current screening programmes and the roll out of any new programme managed effectively. FIT was recommended to replace gFOBt in January

2016, but it has still not been rolled out nationally. Yet Scotland in 2010 – 2012 ran a FIT pilot in two NHS Health Boards, with England running a pilot in 2014, meaning there has been evidence of its benefit for nearly a decade. An organisation must be responsible for horizon scanning of emerging research and future developments to ensure that preparations are made within the service to make safe and swift changes to screening programmes, once the National Screening Committee has made a recommendation.

Moving towards risk stratified screening

Screening involves testing people who are assumed to be healthy, so it is crucial that the benefits outweigh the harms and that the programme is both clinically effective and cost-effective. Advances in research provide a huge opportunity to make screening programmes more intelligent and sophisticated, with the aim of bringing more benefits and reducing harms at both a population and individual level.

Risk stratified screening would help identify those who are at higher and lower risk of developing certain type of cancers based on their genetics, lifestyle and environmental factors as well as their previous screening result. As a result, people at lower risk could be screened less frequently which would provide them with the same benefit while minimising harms such as overdiagnosis. Whereas, screening people at a higher risk more frequently would likely increase the chance of detecting cancer early and free up capacity to be used more effectively elsewhere in the NHS.

The National Screening Committee (NSC) who provide policy recommendations to the Government only consider population-based screening to be within their remit. However, risk stratified programmes do exist within the NHS. The National Institute for Health and Care Excellence (NICE) provide guidance on screening people considered at high and moderate risk of developing breast cancer, and the NHS England Target Lung Health Check programme is aimed at past and current smokers who are considered at higher risk of developing lung cancer.

With the introduction of HPV primary testing in the cervical screening programme, women will be screened at different frequencies depending on their screening result, which determines their risk of developing cervical cancer. This was recommended by the NSC based on robust evidence. In the future, this should be combined with HPV vaccination status, as women who have been vaccinated and are HPV negative may need a reduced number of screens in their lifetime^v.

While there is, rightly, a move to risk stratification within existing screening programmes, it is unclear which body considers the introduction of new cancer screening programmes which operate on the principle of enhanced risk stratification that is based on more than age and sex. It is imperative that there is a decision-making body that considers risk stratified screening for individuals considered at higher risk.

We value the objective and robust assessment of the evidence and balance of benefits and harms the National Screening Committee provides to screening programmes. It is a mechanism by which national funding is secured to ensure national roll out while providing high quality assurance and safety of delivery to yield the balance of benefits and harms that is expected from the programme.

There would therefore be clear benefit to expanding the remit of the UK NSC to include risk stratified screening. Regardless of where the locus of decision-making is, there needs to be a more

coordinated approach to all cancer screening, making screening of high-risk individuals subject to the same quality assurance as current national programmes.

Investment required in a new and robust IT infrastructure

Due to the failures of the IT system in 2018 and the fact that the existing IT system cannot deliver basic interventions such as text reminders, we believe that investment in a new robust IT system which is fit for purpose and the future of the cancer screening programmes is a necessity. The IT system must be able to correctly identify all eligible participants for screening to ensure equity of access and help reduce health inequalities. Participants are identified by their GP record so to be invited for screening they must be registered at a GP practice with a correct address. Yet some people are not routinely offered screening as their GP record does not identify them as eligible. This is the case for some trans men who routinely do not receive their invitation to cervical screening, as their GP records marks them as male.

The identification of eligible participants will be crucial as screening moves towards more stratified approaches but will also be reliant on having up to date and reliable GP records linked with, or potentially integrated with the screening IT system. This must include smoking status and history and HPV vaccination status and consider future developments such as genetic testing.

We would like to see one integrated IT system for all existing and future cancer screening programmes and patient records. This would allow GPs to be able to see individuals' participation across all programmes they are eligible for providing an opportunity for a discussion about taking part. An integrated system would provide researchers with robust data on uptake, screening results and any risk factors which may increase or decrease cancer risk. All previous screening results along with any follow up investigations and treatments required should also be included.

Increase uptake and reduce health inequalities

There are opportunities to improve the effectiveness of current screening programmes even before making changes to the operation of the programmes.

Increasing informed uptake would contribute to preventing more cancers and diagnosing more cancers earlier. For example, current uptake in the bowel cancer screening programme is 59%, against a national target of 75%. Reaching this target would mean significantly more opportunities to diagnose bowel cancer at an early stage. Cervical screening coverage is now at a 20 year low, with coverage in 2017/18 (71.4%) significantly below the 80% standard.^{vi} There are barriers and misunderstandings which serve to deter participation in the screening programmes and which undermine the principles of informed choice and equity of access.

Barriers to taking part in screening programmes vary depending on each programme so we would welcome efforts, both at a local and national level, to tackle these as this would go some way to reducing health inequalities.

The provision of accessible, accurate information is key to reducing barriers to screening. Cancer Research UK is active in providing this information. We have partnered with Public Health England, NHS England and the Department of Health and Social Care to run bowel cancer screening advertising campaigns in 7 regions in England in 2015/16 and in the North West in 2017^{vii}. Similarly, a pilot in London tested several interventions to increase bowel screening uptake, such as CRUK endorsement flyers, 'enhancement kits' to make providing samples easier, and advertising^{viii}.

The Cancer Research UK Facilitator Programme works directly with GP practices, CCGs and others to support informed uptake of screening programmes^{ix}. Independent evaluation of the programme has found that GP practices attributed increases in bowel screening of up to 17% to working with Facilitators^x. This work has informed our view of how barriers to screening should be removed and should be considered by this review.

Reducing barriers to screening also means ensuring an acceptable test is widely available for the eligible population. For example, FIT screening is associated with improved uptake, as it requires only one stool sample compared with the 6 for the current guaiac test. For every month that the introduction of FIT is delayed in England, we are not seeing the benefits of an estimated 26,000 extra people taking part in the bowel screening programme.

Those who do not participate tend to be from lower socioeconomic backgrounds and tend to be older, male or from ethnic minority backgrounds. Low health literacy and numeracy of participants along with fear and denial around the test outcome are all barriers for people taking part in bowel screening^{xi}. The evaluation of pilot interventions must be supported, and interventions found to reduce barriers to uptake should be rolled out where appropriate.

We advocate that taking part in screening must be an informed choice by all participants, who are fully aware of the benefits and harms. NHS England and Public Health England must ensure that people are fully aware of the programmes and what they are screening for, and that any barriers to participation have been minimised.

While IT infrastructure is developed, there are opportunities to capitalise on the principle of Making Every Contact Count, by encouraging and supporting NHS staff to proactively raise the topic of cancer screening with their patients, answering any questions, dispelling any myths and tackling fatalistic beliefs. Patients' screening records should be integrated across all NHS services, with a flag in the record for patients who have not taken part in screening within 6 months of receiving their invitation.

Offering a patient-centred approach to cancer screening, which makes things as easy as possible for the individual, is welcome, but such innovations will require robust underpinning IT infrastructure. A robust IT system must support both a national and local dashboard on current uptake with the ability to break it down by demographics, including ethnicity, to help determine those not taking part in screening at a local level. It would also provide timely insight on the impact any interventions undertaken have on uptake.

Increasing capacity in screening services

Workforce shortages, especially in diagnostic services, are threatening all aspects of the cancer pathway, and in some cases may be preventing improvements from being made. Research commissioned by Cancer Research UK has found that there are workforce shortages in the three key diagnostic professions that support cancer screening programmes – imaging^{xii}, endoscopy^{xiii} and pathology^{xiv}. More recently, Cancer Research UK estimates suggested that the cancer workforce may need to double by 2027 just to keep pace with the increasing numbers of patients being diagnosed with cancer, without improving services^{xv}. Improvements to services, such as those being introduced in screening programmes, will require even more capacity.

Increasing workforce capacity in screening and diagnostic services is therefore fundamental to optimise the screening programmes and will be required for swift implementation for future screening programmes and changes to existing ones. NHS England and NHS Improvement are currently developing a Workforce Implementation Plan to address workforce shortages in the NHS. The long-term element of this plan must include a clear plan for growing the cancer workforce, including those working within screening services. This plan must ensure that in the future, capacity in diagnostic screening services does not prevent the roll out of new, better tests or the implementation of new screening programmes.

The implementation and optimisation of the bowel cancer screening programme has been stifled by capacity in screening endoscopy services. This is also evident in the roll out of bowel scope and the decision to bring FIT in at a higher threshold than Scotland, who introduced the test in November 2017 at a threshold of 80 ug/g. The decision to bring in FIT screening in England at a threshold of 120ug/g was made in part due to the constraints in capacity in screening endoscopy services, rather than on the benefit to patients. Efforts must be coordinated and accompanied by investment to increase capacity in endoscopy and pathology services to ensure the threshold of FIT can be lowered to detect more cancers at an earlier stage.

Clinicians require additional training to report on screening tests and perform follow up tests after an abnormal result. The training and employment of more staff in diagnostic services must be accompanied by efforts to increase the number of staff working in screening. This should include training programmes for clinicians in conjunction with upskilling other NHS staff such as the nurse endoscopy training programme. We welcome this programme but understand that this has not as achieved planned numbers due to Trusts being unable to release staff as they do not have the staff and finances to backfill the role. The Government should provide Trusts with additional funds to ensure that staff can undertake further training without the concern that the service will suffer.

Careful thought must be given on how artificial intelligence can assist and enable clinicians to deliver screening programmes. Artificial intelligence will not replace clinicians but in some circumstances can deal with any tests which have clear normal results, increasing clinician time spent on reporting on tests which may have an abnormal result. Optimam, a Cancer Research UK funded study, is an extensive mammography image database created to support research to optimise the adoption of new X-ray technology for detecting breast cancers and thereby improve the early detection of breast cancers in the NHS Screening Programme. This type of technology should be adopted, where appropriate, to assist clinicians and improve the early detection of cancers.

Consideration must also be given to the model used for commissioning of screening services as it can have a negative impact on the capacity to deliver follow up tests to an abnormal screening result. Currently screening colonoscopy services are paid through block contracts so unexpected pressures such as increased patient demand or cost of care are not considered. Providers have very limited mechanisms to mitigate these pressures. The introduction of FIT this year will result in increased referrals so it is vital that the funds are available to cover this increase.

Block contracts have also been critiqued for not incentivising improved clinical care or efficiency. Perversely block contracting means that by performing less well, and thereby attracting fewer patients, providers can reduce their financial pressures. In addition, block contracts allow no flexibility for capital finance or innovation where upfront investment is required, as this would directly take away from delivering a service.

Intelligent approaches to research and policy

We would like to see a more intelligent approach to conducting research within screening programmes. By integrating research as a core pillar of a programme, it would allow for the research to be conducted and evaluated in parallel to the programme, rather than independently. This would help expand the evidence base and inform policy recommendations. For example, there is an opportunity to integrate research by randomising the roll out of FIT when lowering the age of the bowel screening programme to 50. This would allow the investigation of risk stratified approaches for people younger than the current screening age of 60. However, this would require good quality and complete data to be available.

Research and implementation of the use of intelligent algorithms that have the potential to radically optimise screening programmes will be limited by the data available on patient demographics and other risk factors. Data collection and integration of patient health records must be improved and complete, including ethnicity, if research can be adequately conducted within the screening programmes.

As a research organisation we would like to see increased transparency of how to access data and increased accessibility of the data collected within the screening programmes for researchers. By freeing up access to data for researchers it would make it easier to randomise patients for research trials adding to the evidence base.

About us

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer and this is achieved through the work of over 4,000 scientists, doctors and nurses. In 2017/18, we spent £423 million on research institutes, hospitals and universities across the UK.

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ⁱ National Cancer Intelligence Network Registration and Analysis Service. [Routes to Diagnosis 2006-2013/2016 workbook \(a\)](#). London: NCIN; 2015PHE; 2018

ⁱⁱ National Cancer Intelligence Network Registration and Analysis Service and Cancer Research UK. Stage by [Routes to diagnosis of cancer by stage, 2012-2013, 2015-2016 workbook](#). London: NCIN; 2016PHE; 2019

ⁱⁱⁱ Cancer Research UK estimates, 2018, unpublished.

^{iv} Based on data for 2017/18 from NHS digital breast screening programme <https://digital.nhs.uk/data-and-information/publications/statistical/breast-screening-programme>, 2017/18 NHS digital cervical screening programme <https://digital.nhs.uk/data-and-information/publications/statistical/cervical-screening-programme> and 2017/18 NHS Screening Programmes in England <https://www.gov.uk/government/publications/nhs-screening-programmes-annual-report>. Breast (aged 50-70 years), Bowel (aged 60-74 years) and Cervix (aged 50-70 years).

^v <https://onlinelibrary.wiley.com/doi/full/10.1002/ijc.31094>

^{vi} <https://phescrining.blog.gov.uk/2018/11/30/phe-to-launch-national-cervical-screening-campaign-in-march-2019/>

^{vii} https://www.cancerresearchuk.org/health-professional/awareness-and-prevention/be-clear-on-cancer/bowel-screening-campaign-england#BCOC_bowel_screening_essential2

^{viii} <https://www.cancerresearchuk.org/health-professional/screening/bowel-screening-evidence-and-resources/past-bowel-cancer-screening-campaigns#bowelscreening2014Londonpilot0>

^{ix} https://www.cancerresearchuk.org/health-professional/learning-and-support/about-our-partnerships/what-is-the-facilitator-programme#About_Facilitator_programme1

^x <https://www.cancerresearchuk.org/health-professional/learning-and-support/about-our-partnerships/how-we-know-the-programme-works>

^{xi} <https://www.cancerresearchuk.org/health-professional/screening/bowel-screening-evidence-and-resources/evidence-on-increasing-bowel-screening-uptake#bowelscreeningbarriers0>

^{xii} https://www.cancerresearchuk.org/sites/default/files/horizon_scanning_-_final.pdf

^{xiii} https://www.cancerresearchuk.org/sites/default/files/scoping_the_future_-_final.pdf

^{xiv} https://www.cancerresearchuk.org/sites/default/files/testing_times_to_come_nov_16_cruk.pdf

^{xv}

https://www.cancerresearchuk.org/sites/default/files/securing_a_cancer_workforce_for_the_best_outcomes_november_2018_full_report.pdf