Department of Health & Social Care

From Rt. Hon Andrew Stephenson CBE MP
Minister of State for Health and Secondary Care

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Rt Hon Caroline Nokes MP

Chair of the Women and Equalities Committee

Monday 25th March 2024

Dear Caroline,

Response to the Women and Equalities Committee – Breast Screening

My honourable friend the Minister for Mental Health and Women's Health Strategy Maria Caufield MP spoke at the Women and Equalities Committee on Wednesday 6th March. However, the committee was unable to cover all the items on its agenda and you wrote in your capacity as Chair of the Committee on 7th March seeking answers to some questions relating to Breast Screening. As the Minister responsible for Screening I have taken it upon myself to provide you with a thorough response to these questions which I hope you and the committee will find helpful.

Uptake in breast Screening Programme

Q: Why is the NHS struggling to meet its target of 70% of invited women attending breast cancer screenings?

Breast screening services were significantly impacted by the COVID 19 pandemic, pausing sending invitations for approximately 3 months resulting in a backlog of women. A national restoration plan with targeted support was put in place by NHS England to support all breast screening services to clear the backlog by the Summer of 2023.

Pre-pandemic the overall 70% acceptable threshold target for uptake was being achieved, however, there was variability across England. The round length (appointment offered within 36 months of a previous screen) was not being achieved pre-pandemic; Data from NHSE shows that 84% were achieving the round length in, Q1, 2019/20. The NHSE national restoration plan implemented in 2020/21 aimed to deliver activity above average pre-pandemic levels whilst supporting acceptable levels of uptake. NHSE have stated for Q1 23/24 round length recovered to 89.9%, and further published data for Q2 is expected shortly. The national round length target is 90%.

NHSE have developed an iterative uptake improvement plan in collaboration with key stakeholders that will be published in 2024/25, utilising evidence from a series of academic evaluations commissioned from the Wolfson Institute of Population Health.

The actions and priority plans include:

- A series of national evaluative projects in representative breast screening services reporting in April 2024, which will provide evidence to underpin future pathway changes, and improvements in the national screening programme, specifically:

    - to understand the impact of different invitation methodologies with reference to factors such as age, previous screening history (attendance at first invitations/subsequent invites) and deprivation in 7 breast screening services
    - to understand the impact on screening uptake of processes to actively follow up women who have missed an appointment or not engaged with the service in 12 breast screening services
    - a review to ascertain the reasons why women do not attend screening to address any barriers via an online survey to over 17,000 women

- data and analytics work which commenced in 2023/24 and has provided GP practice level data for regional commissioning teams and providers to support local action plans and initiatives. The workplan is utilising analytical tools and approaches developed during the COVID-19 pandemic, with plans to provide ethnicity estimate data in 2024/25
- A completed behavioural insights literature review on the barriers to uptake of breast cancer screening among women invited for the first time. The findings are expected to report in 2024/25 which will enable the development of the targeted communication strategies to support breast screening attendance for women and individuals, particularly those being invited for the first time.
- A completed review of the invitation letter with a focus group led by Ipsos Mori to explore views, barriers and enablers to attending breast screening appointments and gather reaction to communications to inform the wider initiative to be compliant with the Accessibility standard and communication strategy
- NHS England Learning and Disability team workshop for providers on supporting people with Autism attending breast screening to improve patient experience, and implementation of local uptake improvement plans
- Launching a Futures NHS page to share learning on uptake improvement with regional teams and providers
- Commenced work on the IT solutions to support improvements for Breast Screening and other Programmes via the Digital Transformation of Screening (DToS), DToS will digitally enable the NHS to deliver simpler, safer and efficient user focused screening services to prevent or diagnose conditions early when treatment is more successful. In the first instance support the cohorting, invitation and communication with participants.

Activity within the breast screening programme in 2021/22 and 2022/23 was higher than the previous 10 years. There were more women invited for breast screening in the fiscal years 2021/22 and 2022/23 (3.17 million and 2.98 million respectively) compared to pre-pandemic years (2.56 million in 2018/19 and 2.60 million in 2019/20). There were also more women screened within 6 months of their invitation in 2021/22 and 2022/23 (1.97 million and 1.93 million respectively) compared to 2018/19 (1.82 million) and 2019/20 (1.79 million), but uptake remains lower than it was before the pandemic (64.6% in 2022/23 compared to 71.1% in 2018/19).

This is the issue that the above activities seek to understand the cause of.

Breast Screening Improvement Plan

Q: What specific steps are you taking in those parts of the UK, such as central London, and in those communities where take up is substantially below target?

NHSE have indicated that all the NHS regional teams have developed comprehensive plans to improve uptake. In London (the region with the lowest uptake) their plans include;

- setting up health promotion leads in each of the Breast Screening services, with funded training.
- Joint working with the Legacy and Health Equity Partnership to access and engage with communities identified as having low uptake and barriers to access.
- Driving improved engagement and joint working across Integrated Care System partners, with clear and coordinated system level priorities and actions to improve uptake and reduce health inequalities, owned and monitored by local partners.
- Development of a Primary Care Engagement Pack to enable GP Practices / PCN staff to better support and signpost patients to screening services in London.
- Development of a London Breast Screening Communication Toolkit, providing information and resources for NHS staff, charities, and voluntary organisations at local and regional level to work together to support improvement projects and to increase uptake across the capital.

The North West region has similar plans.
Greater Manchester commissioned geospatial mapping to identify the cohorts who are not accessing breast screening, alongside commissioned activity with the 'Answer Cancer service', to provide coordinated cancer screening prevention and screening awareness engagement in communities with low uptake, using a diverse range of approaches and interventions. These interventions and other activity have had a significant impact with uptake moving from 58.1%, 2020/21 to 66.7%, 2022/23.

Q: We understand that the NHS has a plan to improve take up. Can you share that plan with the Committee?

NHSE will publish a plan in 24/25, developed in collaboration with key stakeholders to improve uptake within the breast screening programme, noting 2028 Cancer Early Detection targets. The plan sets out the priorities, interventions and monitoring of impact and outcomes to be achieved to improve uptake through:

- Expanding access: moving forward with modernisation of the breast screening programme where there are barriers to accessing appointments, especially focusing in low uptake areas/groups.
- Data and analytics: ensuring we have the availability of population level data (protected characteristics e.g., ethnicity & IMD, GP level) to show insights into uptake and support services to deliver targeted initiatives to improve uptake.
- Reducing inequalities: increased use of evidence based and evaluated interventions to address inequalities and barriers to accessing breast screening.
- Contracting: strengthening contracting mechanisms where appropriate to improve uptake.
- Communication: ensuring the programme has the correct inclusive and accessible communication mechanisms and materials to support a modern breast screening programme; leaving no one behind, sharing resources, learning and best practice across key stakeholders to help raise awareness and improve uptake.

- IT developments: continuing development of the breast screening IT systems, in addition to the DTOS programme, ensuring the best application of the current IT systems is in place to improve uptake.

Appointment System

Q: Whether there has been a change to the appointment process from a set time to an open appointment and, if so, what assessment you have made of the impact of that change on take up rates?

NHSE recommend a change to the appointment process for all services during COVID-19 pandemic; moving from fixed (an invitation is sent with a fixed date/time appointment) to open (an invitation is sent inviting women to call and arrange a screening appointment convenient to them). The decision was based on clinical advice in order to ensure full utilisation of available appointment slots; The rationale was that women who arrange their own screening are more likely to attend, therefore less unused breast screening appointments slots would be wasted, and maximum capacity is utilised.

As services restored some services retained the open appointments e.g. Majority of South West Region services because of noted positive impact on uptake (63.9 %, 2020/21 to 66.8 %, 2022/23). Other regions services reverted to timed appointments based on local assessment of need. The commissioned evaluation by NHSE will support the assessment of the appointment process, and allow them to make an evidence-based decision on the optimum method of inviting women. It is due to report by April 2024.

Q: Are all appointments offered at a set time or are they an open invitation? [If the latter, does that impact on take up?

NHSE have advised that the type of invitation adopted by each screening services post COVID-19 pandemic is based on an assessment of need locally, so there is currently a mix of open and timed appointments across England.

The evaluations will provide some evidence of the impact of the different invitation methodologies on screening uptake, alongside a planned survey in 2024/25 of services to identify the methods adopted across England

Cost of Living and funding

Q: To what extent is a lack of take up a consequence of increased pressures on the cost of living?

It is not possible to gauge the extent to which cost of living has impacted take up. However evidence suggests that breast screening uptake is better in more affluent areas, even though breast cancer affects all socio-economic groups.

Research also shows women are more likely to attend for breast screening if they have access to a car; this can be an issue in rural areas.

Child care arrangements and not being able to take time off work are contributing factors in people choosing whether to take up an appointment.

Mitigations offered in some areas include clinic hours at evenings and weekends; mobile screening to bring the equipment closer to women; and ride share schemes to assist with travel.

Q: What additional funding are you making available to support increased take up of breast screening?

As part of the Women's Health Strategy for England published on 20 July 2022, it was announced that £10 million would be invested for breast screening units in areas with the greatest challenges in screening uptake and recovery from the COVID-19 Pandemic.

The £10 million investment funded 28 new breast screening units and nearly 60 life-saving upgrades to services in the areas where they are most needed, so more women can be checked for signs of cancer, speeding up diagnosis and treatment.

In addition nearly £9 million in capital funding via the NHSE Diagnostics Transformation Initiative has been given to providers to utilise to support breast screening services.

In terms of overall strategic impact, increasing the number of units, and therefore the sites and accessibility of the service serves to address 3 key Departmental priorities:

- Increase uptake of screening in lower uptake areas such as rural and less affluent areas;
- Accelerate the restoration of the breast screening programme following the COVID-19 pandemic, aiding those most at need while preventing the creation of a post code lottery in service provision; and.
- Help address the requirement to support early diagnosis of cancer as set out in the NHS England Long Term Plan (LTP)

<u>Breast Screening Incident</u>

Q: The Statement said that in 2003 clinicians were asked to contact patients at high risk of breast cancer. Can you set out why many women did not then receive the annual screening they needed

The affected women were treated between 1962 and 2003. A patient notification exercise in 2003 sought to identify these women. Results of research published in 2009 (Howell SJ, British Journal of Cancer, 101, 582-588) showed that although screening was successful in terms of detecting early stage cancers, the reach of screening in the at-risk population was low. This was due to patients being discharged from hospital care or moving to another part of the country, GPs being unaware of the screening guidelines, or oncologists retiring, changing roles or forgetting to refer when a woman became eligible for screening.

In 2018 a specific systematic approach called BARD (Breast screening After Radiotherapy Dataset) was set up between the Christie, Manchester University and the National Disease Registration Service (NDRS) to make sure eligible patients were informed of screening options at the right time. BARD became fully operational in January 2021.

There are no centrally held records which detail whether these women were referred for surveillance and, if so, what surveillance they were offered and for how long. What has been identified is that a number of these women were not then referred for screening

following the transfer of responsibility of screening women at very high risk of breast cancer into the NHS breast screening programme.

Q: For what reasons it took another 20 years to find out that thousands of women had missed out on essential screening?

In 2003, the Chief Medical Officer commissioned a patient notification exercise (PNE) and the process of identifying women was co-ordinated by the then cancer networks and surveillance for this group of women was conducted through symptomatic services. Women do not start annual MRI testing immediately following treatment – but between 8 and 15 years after treatment depending on their age at the time they were treated. This is because the increased risk does not emerge until approximately 10 years later.

In 2007 the Department of Health's Cancer Reform Strategy (CRS) was published which indicated that the way surveillance was conducted for women at very high risk of breast cancer in the symptomatic breast service was variable, and it recommended that the NHS breast cancer screening programme took responsibility for annual testing for women referred to it.

NHS England was established in 2013 and took over responsibility for commissioning NHS Breast Screening services as part of its delegated public health responsibilities under s7A of the 2006 Act. In 2015/16 NHS Breast Screening Programme took on responsibility for very high risk screening in line with Cancer Reform Strategy guidance having undertaken pilot work and put in place the necessary IT changes and the appropriate clinical pathways. Before 2021, the NHS Breast Screening Programme was reliant on referrals from individual genetic services, family history clinics and radiotherapy centres and relied on women that are at very high risk being identified by the centres and being referred to the local Breast Screening Office (BSO) who undertake checks to ensure that the woman meets the requirements of the programme, and if confirmed, they are logged into the screening IT system and called/ recalled annually.

To improve the identification and referral of women, following a pilot in 2018, the Breast Screening after Radiotherapy Dataset (BARD) team (an initiative led by a team of oncologists and data analysts in Manchester) became fully operational in 2021. BARD is a confidential database of women in England who have received radiotherapy involving breast tissue when aged between 10 to 35 years. It uses national datasets that are now available and undertakes checks with treating centres to ensure all women at increased risk of breast cancer following radiotherapy are referred to the NHS Breast Screening Programme in line with national guidelines.

It is these two improvements (the establishment of BARD and the NHS' introduction of a VHR pathway) that has allowed us to identify the issue. Once BARD was established they reviewed the data originally collected by researchers in 2003 to check whether eligible women had been referred to the VHR pathway and identified this issue. Details of this were shared with NHS England in late September 2023 and since then detailed analysis of data across multiple IT systems has been undertaken to triangulate information about clinical history, current status and residency in order to identify the identity of the individuals in the affected cohorts and to ensure the appropriate follow up was put in place.

Q: Why two further cohorts of women, those treated between 2003 and 2013 and 2023, have also been missed?

Unlike the call recall system used in the routine breast screening programme and before 2021, the NHS Very High Risk Breast Screening Programme was reliant on receiving referrals from individual genetic services, surgical and oncology consultants family history clinics and radiotherapy centres and relied on women that are at very high risk being identified by the centres and being referred to the local Breast Screening Office who undertake checks to ensure that the woman meets the requirements of the programme.

To improve the identification and referral of women having previously had radiotherapy to breast tissue, in 2018 a specialist team was set up to make sure eligible patients were identified both retrospectively and prospectively and informed of screening options as soon as eligibility was established to provide a route to appropriate screening. This ongoing activity involved auditing information from various sources (including predominantly the cancer registry and radiotherapy centres), to ascertain which women were eligible for referral into the high risk programme. Women identified post the 2003 PNE cohort could have been undergoing surveillance outside of the VHR programme but the specialist team (BARD) were able to identify whether they were in the national VHR programme as part of their due diligence and refer where appropriate.

Most women treated between 2003 and 2023 will be on the correct VHR pathway. The exercise being undertaken is to provide assurance that this is the case and identify a small number of women who may have been missed.

Q: How many of the 1,487 women being contacted are not yet receiving screening on a three-yearly basis?

The majority of this cohort were receiving routine breast cancer screening on a 3 yearly basis. 252 women were not part of any NHS BSP surveillance (routine) due to the majority being under the age of eligibility for the routine screening programme. Others were not registered with a GP practice and consequently could not be invited for screening.

Q: Of the 647 women who had had a diagnosis of breast cancer in 2015, in how many of those cases would cancer have been detected earlier if they had received annual screening?

Without knowing the individual clinical history of each patient and the stage at which their cancer was detected it is not possible to answer this question. The NHS has committed to reviewing the cases of individual women with breast cancer to enable this question to be answered on a case by case basis. Where harm is identified, the responsible trust will discharge their Duty of Candour responsibilities and will inform the woman of their findings

Q: The statement set out that women who are known to have had a bilateral mastectomy and those who are known to have had a positive diagnosis will have their cases reviewed. What does that mean in practice and what does it mean for the patient?

The NHS will be carrying out clinical reviews to establish if any women have been harmed. The families of any women deemed to be affected will be contacted as soon as this assessment has been made. The review process will begin with those women diagnosed

with breast cancer prior to this announcement who are currently alive. The second phase will be based on a refined methodology informed by our learning in phase 1. In this phase the cases of those women who died of breast cancer will be reviewed. If harm is identified then the responsible trust will seek to identify the next of kin so as to make a Duty of Candour apology. The final phase will review the cases of any breast cancers identified as part of this catch up activity.

Further information on the clinical reviews carried out will be shared in due course.

I hope that this letter provides the detailed answers you and the committee were seeking. Please do not hesitate to come back to me for anything further.

Yours sincerely,

Rt. Hon Andrew Stephenson CBE MP

Minister of State Health and Secondary Care