PRESS PLAY: GETTING AND KEEPING BREAST CANCER SERVICES BACK ON TRACK
Coronavirus is the biggest crisis that breast cancer has faced in decades.

So, to mark Breast Cancer Awareness Month 2020, this report shares what we are hearing and seeing about the impact of coronavirus on breast cancer, including from breast cancer patients and healthcare professionals.

As the number of cases of coronavirus begins to increase again the Prime Minister has warned that a second wave is coming. The number of local lockdowns is increasing. There is speculation about further possible measures which may be introduced to control the virus. And concerns over winter pressures on the NHS continue to grow.

Earlier this year, at the height of the pandemic, we saw a big drop in the number of people being referred to see a specialist with suspected breast cancer. Screening services were paused. Recruitment to many clinical trials was paused. And while many patient's treatment continued unchanged other patients saw delays and cancellations to their treatment alongside changes to the support they received. This has caused huge levels of anxiety - particularly for patients with incurable secondary breast cancer and their loved ones.

Breast Cancer Now’s world-class research and life-changing community support services are here for anyone affected by the disease, but they have been deeply affected. And the fundraising that powers them has also been hit hard, too.

But, gradually, ‘play’ is being pressed for breast cancer services and research. The number of referrals continues to recover every month. Breast screening is restarting. The number of people beginning treatment is rising. Our researchers are back in the lab - although we have had no option but to reduce the amount we spend on research. And we have developed new online support services to continue to be here for anyone affected by breast cancer.

The resource and effort the NHS has put into finding ways to safely diagnose and treat cancer during the pandemic, and the knowledge we have gained, will prove invaluable moving forwards. We must make sure we are well prepared for a second wave. The progress that we have made in breast cancer must not be allowed to stall. We cannot afford to pause again.

This report makes a number of recommendations to help ensure this does not happen. We look forward to working with governments and the NHS across the UK to implement them.
At the start of this year, as the number of coronavirus cases began to grow, it became very clear, very quickly that the pandemic would have a huge impact on breast cancer.

In March, to help us understand this impact, we asked people with breast cancer to tell us how coronavirus had affected their treatment and care. 580 people responded. Many reported that they or their loved ones had experienced delays or cancellations to treatment and monitoring scans. Others had not experienced any changes to their treatment.

To understand how people’s experiences may have changed and try to better quantify some of the impacts we heard about, we ran a second survey between 9 July and 6 August. The survey was conducted online and publicised through our social media accounts and other networks including our Insight and Experience Panel and Breast Cancer Voices network. 2,124 people with breast cancer responded.

We also spoke to 12 healthcare professionals from different parts of the breast cancer pathway including radiographers, surgeons, oncologists specialising in drug treatment and radiotherapy, and clinical nurse specialists. We supplemented this by looking at the data available on the impact of the pandemic, for example on referrals to see a specialist.

This report sets out what we found, and what we think needs to happen next to tackle the challenges we have identified.

Secondary breast cancer
In Breast Cancer Awareness Month 2019 we launched a campaign calling for action to address the challenges experienced by patients with incurable, secondary breast cancer. These include receiving a prompt diagnosis, access to treatments, information about
clinical trials and support from a clinical nurse specialist. Breast Cancer Now is committed to campaigning to ensure these challenges are addressed.

Our analysis of responses to our survey on the impact of coronavirus did not find significant differences for patients with secondary breast cancer.

Back in May we highlighted that the specific needs of patients with secondary breast cancer must be identified and addressed in the recovery plans for cancer that are being developed by governments and the NHS across the UK. However, this will be hampered by the lack of available data on secondary breast cancer patients – including the number of people living with the disease, which we highlighted in this campaign. This makes it extremely difficult to plan services. We are currently calling for a national audit of secondary breast cancer to be funded as part of the Comprehensive Spending Review expected in the Autumn.

As part of our campaign we also highlighted that less than a third of secondary breast cancer patients said they regularly saw a clinical nurse specialist (CNS). Worryingly 41% of respondents to our survey felt they had less contact with their CNS during the coronavirus outbreak. We are also calling for funding to recruit and train more CNSs to meet the needs of all people living with breast cancer as part of the Comprehensive Spending Review.

THE SURVEY IN NUMBERS

2124 people with breast cancer responded to the survey

1545 had primary breast cancer, and 472 had secondary breast cancer, also known as advanced, stage 4 or metastatic breast cancer. The remainder chose to describe their breast cancer themselves.

354 were diagnosed with breast cancer between January and July 2020

226 respondents from England

1708 respondents from Scotland

43 respondents from Northern Ireland

147 respondents from Wales
DIAGNOSIS
The earlier breast cancer is diagnosed, the more likely it is that treatment will be successful.

As the number of referrals to see a cancer specialist continues to recover and the breast screening programme restarts there is likely to be an influx in demand for imaging and diagnostics which threatens to overwhelm these services. It is vital that that the recovery plans being developed by governments and the NHS across the UK set out how this expected surge in demand will be managed so people are diagnosed and start treatment for their breast cancer as soon as possible.

Capacity in the diagnostic workforce must also be assessed, and plans put in place to address shortages, backed up with investment through the upcoming Comprehensive Spending Review.

Referrals
The number of people referred to see a specialist with suspected cancer declined dramatically during the peak of the coronavirus outbreak in April, with a drop of around 70% across all cancers being reported in some parts of the UK. In England, between March and July 2020 there were over 95,000 fewer referrals by a GP for tests (whether breast cancer was initially suspected or not) compared with 2019. In Wales between March and July there were 2,500 fewer urgent suspected breast cancer referrals. Full data for this period has not yet been published for Scotland and Northern Ireland. However, we estimate that across the UK there is likely to have been nearly 107,000 fewer referrals.

A survey undertaken for NHS England suggested that the main reasons people were reluctant to come forward were both concerns about catching coronavirus and giving it to their family, as well as fears they would burden the NHS. Some GPs may also have been reluctant to refer people to hospital.

Across the UK, the NHS launched campaigns to encourage people to come forward with any symptoms that might be cancer. Whilst the number of referrals continues to increase every month, they remain some way below what we would expect in England. It is therefore important that these campaigns continue, particularly during any further peaks in the pandemic.

During the pandemic referrals have been triaged. Those considered to be at high risk of having breast cancer are asked to come in for assessment, whilst those considered to be at low risk of having breast cancer may have a follow up by phone. It is crucial that where assessments are delayed people are monitored and followed up.

‘The new way of triaging has been positive for both staff and those being referred. We simply don’t have the space or the staff to go back to the previous way of dealing with referrals.’
Nicky Roche, consultant breast surgeon
Waiting times

In England and Northern Ireland those referred by their GP should have their first appointment with a specialist within two weeks. Since April, performance against this standard has largely been maintained at pre-pandemic levels. The combination of far fewer people being referred, and telephone triage counting as a first appointment for the purposes of the two-week wait will have helped achieve this.

There is not currently a waiting time target for diagnosis. 354 respondents to our survey (17%) told us that they were diagnosed with breast cancer between January and July: 306 of these (86%) told us they received a diagnosis within 3-4 weeks of being referred for tests.

Breast screening

The breast screening programme was officially paused in Scotland, Wales and Northern Ireland, and effectively paused in England, in March. Screening is now restarting, although this is happening more quickly in some parts of the country than others.

We estimate that a significant backlog of nearly a million women requiring screening has built up across the UK during the pause. It is currently unclear how long it will take to catch up. The number of appointments available has been reduced to enable social distancing and infection prevention and control measures to be implemented, and these arrangements will need to be kept under review.

‘Screening diagnoses around 19,000 breast cancers a year in England and there has been a delay of over 4 months in the programme. To not only maintain pre-pandemic levels of activity, but also do a huge catch up with inadequate workforce levels is an enormous mountain to climb.’

Mary Wilson, consultant breast radiologist

‘I was diagnosed just before lockdown. If I didn’t have the screening I would still be unaware of my diagnosis.’

Survey respondent

Some measures have been taken to try and ensure attendance at the reduced number of appointments available. In England, from the end of September to the end of March 2021 women will be sent ‘open invitations’ to call and make an appointment for screening, rather than a timed appointment. Although women may be more likely to attend an appointment they have made, research shows that the number of women making appointments is significantly lower than those attending timed appointments. We are concerned that this could worsen the persistent decline we have seen in uptake of breast screening in recent years. We are particularly concerned about the impact this will have on groups amongst which uptake is already low, such as women living in deprived areas and some Black and Minority Ethnic (BAME) groups.

If open invitations are to be adopted, then measures must be taken to mitigate the potential impact by implementing measures shown to improve uptake, such as appointment reminders and letters from GP practices endorsing screening. They should also be for a limited period, as proposed. Outcomes must be carefully monitored at a local level. We understand that several services will be early adopters of open invitations and it is essential that we learn from and share the
experience in these areas. For example, in Greater Manchester two members of NHS staff have been appointed to undertake health promotion activities, including calling women that have been invited to make screening appointments, but have not, targeting the most deprived areas.

**Demand for imaging and diagnostics**

The expected increase in referrals and backlog of women waiting for breast screening will lead to an increase in demand for diagnostic and imaging services in the coming months. The workforce in these services was already stretched before the pandemic. For example, a quarter of trusts and health boards across the UK have at least one vacant breast radiologist role, and vacancies are set to increase as a quarter of breast radiologists are expected to retire over the next five years. Many staff may also be suffering from burnout from the demands placed on them during this time.

Combined with a reduction in the number of people that services will be able to see as a result of infection prevention and control measures, we are concerned that this demand threatens to overwhelm services and may lead to people waiting longer to be diagnosed and receive treatment for their breast cancer. The cancer recovery plans being developed by governments and the NHS across the UK must set out how this demand will be managed so that this does not happen.

The new NHS People Plan for 2020/21 in England recognised the severe pressures the NHS workforce has been under during the outbreak – which could be intensified if lack of access to coronavirus testing means staff must self-isolate - and set out broad ambitions to recruit more staff. However, further action is urgently needed in the short and longer-term across the UK to ensure there is an appropriately resourced workforce. Without this recovery plans could be undermined and we risk failing to achieve broader ambitions on early diagnosis, treatment and care.

‘Across the board it has been extremely challenging for the workforce. Ultimately, we are significantly under-resourced. The People Plan doesn’t go far enough, but if I’m being an optimist, every little helps. The NHS can’t squeeze much more out of us; more equipment can be given but you can’t run it without a fully resourced workforce.’

Dr Caroline Rubin, clinical radiologist

### WHAT NEEDS TO HAPPEN NOW?

- The NHS across the UK should continue to encourage people who have symptoms that might be cancer to contact their GP surgery to get them checked out.

- The recovery plans for cancer being developed by governments and the NHS across the UK must set out how the expected influx of demand for imaging and diagnostics will be safely managed.

- Governments and the NHS across the UK must assess diagnostic capacity across breast cancer services and set out a demand-led, long-term plan to ensure the workforce has enough resource and support now and in the future.

- The UK Government must take immediate action as part of the upcoming Comprehensive Spending Review to provide much-needed investment for recruitment in the imaging and diagnostic cancer workforce.

- If open invites are used for the breast screening programme, uptake – including amongst groups already less likely to access breast screening – must be monitored regularly and locally, and measures to mitigate against a decline in uptake implemented. They should also be used for a limited period, as proposed.
TREATMENT
The NHS moved quickly to issue guidance on treating cancer safely at the start of the pandemic.

A significant proportion of respondents to our survey did not experience changes to their treatment. Delays and cancellations to surgery, including breast reconstruction, were the biggest changes reported. Many respondents were concerned about the potential impact of these changes. Recovery plans must set out how treatment will be safely restored to prepandemic levels, and deal with the backlog. Implementation of some beneficial treatment changes, like shorter courses of radiotherapy, were accelerated by the pandemic, and these changes must be able to continue.

Treatment waiting times

Patients should receive their first treatment for cancer within 31 days of being diagnosed, although the target for this varies across the UK from 95% in Scotland to 96% in England and 98% in Northern Ireland. In England the percentage of patients starting their first treatment within 31 days dropped from 97% in February, March and April, to 90% in May but recovered to 95% in July. In Northern Ireland, 95% of patients started their first treatment within 31 days in May and June. Data for Scotland for this period has not yet been published.

Of the 354 respondents that told us they were diagnosed between January and July, 62% said that they had started their first treatment for breast cancer within 3-4 weeks of receiving their diagnosis, with a further 17% starting within 4-6 weeks.

In Wales performance is measured against the target that patients should receive their first treatment within 62 days of being urgently referred with a suspicion of cancer. The number of patients starting treatment in Wales dropped by over a third in April and May compared to the same time last year, but has now recovered, although the percentage starting treatment within 62 days has not been recorded since February.

Experience of treatment

Although 78% of all respondents told us they thought the coronavirus pandemic had an impact on their treatment and care, 52% described their experience during this time as positive or very positive. However, of the 1160 respondents receiving or awaiting treatment only 43% said they definitely felt as involved as they wanted to be in decisions about their treatment and care, compared to 81% of breast cancer patients responding to the Cancer Patient Experience Survey in 2019 in England. This may be related to the fact that many respondents felt they had less contact with healthcare professionals during this time.

95% of all respondents were worried there would be continued pressure on the NHS in the next 12 months, and 88% were worried there would be cancellations, delays and disruption to breast cancer treatment during this time.

Surgery

Surgery is usually the first treatment that most patients with primary breast cancer will have. During the pandemic those with certain types of breast cancer (triple negative and HER2 positive) have been prioritised for surgery. Some patients with hormone receptor positive breast cancer were started on hormone therapy following research which showed that in the majority of cases this could safely delay surgery for at least six months. Risk-reducing mastectomies for women at increased risk of developing breast cancer because of their family history were suspended.

‘Cancer treatment didn’t stop for me during the outbreak, yes it impacted and altered it but I am still here thanks to the NHS still working through such times.’

Survey respondent

43% said they definitely felt as involved as they wanted to be in decisions about their treatment and care.
In the past, some Clinical Commissioning Groups (CCGs) in England have implemented restrictions on the time in which reconstruction should be complete.23 There are already delays of 1 to 2 years for delayed reconstruction in many hospitals. Women waiting for delayed reconstruction should not be prevented from having surgery as a result of any such restrictions.

Of those respondents that experienced changes to their reconstructive surgery nearly half (48%) told us they were unhappy with their body image, and 59% were concerned that they would need more operations as they were unable to have reconstruction at the same time as their mastectomy.24

Patients requiring breast reconstruction surgery, who are often really vulnerable, are at the end of the queue at the moment and could be waiting a long time for their surgery”

Ruth Waters, consultant plastic and reconstructive surgeon and president elect of BAPRAS.

Breast reconstruction
Breast reconstruction was suspended during the peak of the pandemic. Thirty per cent of women that have a mastectomy choose to have breast reconstruction and this is a crucial part of their treatment and recovery from breast cancer.25

21% of respondents that were receiving or awaiting surgery said their breast reconstruction had been cancelled or delayed. We estimate that over 1000 women will have missed out on immediate reconstruction, and around another 500 will have had their delayed reconstruction delayed further.26

Data from NHS England shows that between March and June the number of people having breast cancer surgery was at 76.3% of the level in the same months in 2019.27 The reduced numbers of people being referred and diagnosed during this time, as well as some women being started on hormone therapy instead, are likely to have contributed to this.

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Overall, of those respondents who experienced changes to their surgery, 61% said this had a negative impact on their emotional and mental health, and 62% that it had increased their anxiety. Just over a third were worried about their cancer growing or spreading (34%) and that they may now need more extensive surgery (35%). 41% were worried that the changes would impact on their long-term outcomes from breast cancer. Many people also told us how daunting it was to have to go for treatment alone.25

Guidance on the delivery of drug treatment and interim treatment options to provide greater flexibility in managing cancer was quickly introduced.27 This included reducing the course of adjuvant trastuzumab treatment from 12 months to 6 months which had already been shown to be as effective, whilst potentially reducing the risk of patients having to stop treatment due to heart problems.28 Guidance also suggested how patients should be prioritised for drug treatment if this became necessary. Patients having non-curative treatment, such as those with secondary breast cancer, were generally given a lower priority than those having curative treatment.29 This was hugely concerning and we raised this with governments and the NHS who reiterated the importance of decisions being made on an individual basis according to the risks and benefits of treatment. However, the extent to which this guidance was used in practice is unclear. It is essential that the needs of secondary breast cancer patients are identified and addressed in the cancer recovery plans that are being developed, including recognising the importance of drug treatment for these patients.

Drugs
Drug treatment is a cornerstone of the breast cancer pathway. This is particularly the case for patients with secondary breast cancer for whom drugs can extend the time before their disease progresses and extend their lives.

During the pandemic some patients with both primary and secondary breast cancer had their chemotherapy or targeted treatments changed or temporarily paused, primarily to protect their immune systems. Data from NHS England suggests that in April the number of people starting chemotherapy for breast cancer fell to 61% of levels in April 2019. By June this had returned to 92% of 2019 levels.26
Bisphosphonates
Post-menopausal women with primary breast cancer may also be offered bisphosphonates to help reduce the risk of breast cancer spreading to other parts of the body. Stopping bisphosphonates for this purpose was included in the guidance on interim treatment options during the pandemic issued by NICE and NHS England to reduce the number of people coming into hospital.

Of the 207 women who told us they were receiving or awaiting treatment with bisphosphonates, 50% told us there had been no change in their treatment. Given the most popular frequency for giving IV bisphosphonates is six-monthly, it may be that this has not impacted many women. 29% said their treatment had been delayed. This will likely have been the case for new patients as they should have a dental check-up before starting treatment to help avoid a rare but serious side effect, osteonecrosis of the jaw, and dental services were suspended during lockdown.

Radiotherapy
Radiotherapy is most often given in 15 doses, five days a week for three weeks. Recent results from the FAST and FAST-Forward trials showed that radiotherapy could be just as effective for certain patients given in fewer but higher doses either every day for five days, or once a week for five weeks. The Royal College of Radiologists recommended in March that the results of these trials be implemented in response to the pandemic. 80% of respondents to a survey of radiotherapy units by Action Radiotherapy in April said they had implemented these changes.

Locally we’ve still carried on with treatment for breast cancer patients but there does seem to have been some variation across regions. We changed a small number of drug treatments after discussions with patients, but for the vast majority treatment didn’t change. For chemotherapy we took over a private hospital in order for people to attend their outpatient appointments which helped patients feel safer.

Mark Beresford, clinical oncologist

Of those whose drug treatment was affected as a result of the pandemic, 39% were worried changes would impact on the effectiveness of their drug treatment, and that their cancer would grow or spread as a result, with this being a bigger worry for patients with secondary breast cancer. 43% of those affected by changes were worried it would impact on their long-term outcomes from breast cancer. Nearly half (47%) felt that changes to their drug treatment increased their anxiety, with 41% stating the changes had a negative impact on their emotional and mental wellbeing.
Recovery plans for cancer being developed by governments and the NHS across the UK must set out how treatment will be safely restored to pre-pandemic levels, and the backlog dealt with. This includes women who were unable to have breast reconstruction during this time.

These plans must also identify and address the needs of secondary breast cancer patients, including recognising the importance of drug treatment for these patients.

Women must not be prevented from having breast reconstruction because of any time limits imposed on these operations by CCGs in England.

Some treatment changes introduced during the pandemic, including the reduction in the number of doses of radiotherapy and cycles of adjuvant trastuzumab, have benefits for patients and the NHS and should be enabled to continue with these.
Clinical trials provide a vital opportunity for patients to access potential new treatments at an early stage of their development.

This is particularly important for women with secondary breast cancer, who often have limited treatment options available to them and for whom clinical trials provide precious hope of more time with loved ones. Whilst there was relatively little disruption for breast cancer patients already on clinical trials, the pause in recruitment to many trials will have made it difficult for other patients to access them. The pace at which clinical trials restart must be closely monitored with further measures to assist with restarting considered if necessary. The Government should provide match funding through the upcoming Comprehensive Spending Review to protect vital charity research.

In March, the National Institute of Health Research (NIHR) suggested that many NIHR funded or supported studies may have to be paused as healthcare professionals were asked to prioritise frontline care and make research facilities available for this if asked to do so by their employer. It also paused the site set up of new and ongoing trials.27

The Medical and Healthcare products Regulatory Agency (MHRA) issued guidance on managing trials during the outbreak, including recommendations on remote monitoring.28 48% of respondents to our survey who were receiving treatment through a clinical trial said they were having telephone follow up and interaction instead of face-to-face.

Of 92 breast cancer trials that the NIHR Clinical Research Network was supporting in March 2020, 50% paused recruitment, 45% continued and 5% closed.29 This suggests that there may have been relatively little disruption for patients that were already on trials. Of the 118 respondents who were receiving, or expecting to receive, treatment as part of a clinical trial during this time, just under a quarter (22%) told us they had experienced such disruption. However, this pause in recruitment will have made it more difficult to access trials, and 59% of all respondents were concerned about this.

In conversations with secondary breast cancer patients they have pointed to the speed with which trials for coronavirus have been set up and are keen for the lessons from this to be applied to setting up clinical trials for cancer and other health conditions.

The NIHR published a framework to support restarting clinical trials in May, which is being used across the UK.30 As of September 40% of non-commercial and 57% of commercial studies were open for recruitment in the UK.31

85% of respondents were also concerned about delays and disruption to clinical research into breast cancer more broadly. Like many other medical research charities, the research that Breast Cancer Now funds has been impacted by the estimated drop in our income. Though all our long-term research will continue, we have had to reduce the amount of funding to the Breast Cancer Now Toby Robins Research Centre, Tissue Bank, Generations Study and King’s College London Unit by at least 30%. We have also had to cancel our latest round of project grants and PhD studentships. Cuts to research may in the long-term lead to charities losing the capacity they have built in their research areas, including being unable to support the next generation of researchers.

To ensure that vital research progress does not stall we are supporting the Association of Medical Research Charities (AMRC) call for match-funding from the Government for future charity research through the upcoming Comprehensive Spending Review.

WHAT NEEDS TO HAPPEN NOW?

- The NIHR and equivalent bodies in the nations should continue to closely monitor the restart of clinical trials and publish information on them, and consider if, and what, further measures could be taken to assist with this.
- The Government should match fund future charity research over the next three years via a Life Sciences-Charity Partnership Fund for medical research charities.
- The NIHR and MHRA should consider how the speed with which clinical trials for vaccines and treatments for coronavirus have been set up could be applied to cancer trials.
CARE AND SUPPORT
Living with breast cancer can be incredibly difficult at the best of times. Good care and support can make a real difference.

The pandemic and resulting changes to treatment and care have been a real source of anxiety for many people with breast cancer. Whilst the majority of respondents that accessed support did so through a clinical nurse specialist (CNS), many felt they had less contact with them during this period. It is vital that support services are included in recovery plans. Additional funding to recruit and train more CNSs to meet the needs of people living with breast cancer, including secondary breast cancer, both now and in the future, must be provided through the upcoming Comprehensive Spending Review.

Respondents to our survey felt the coronavirus outbreak had impacted on their care in several ways. These included being unable to access services such as counselling and therapy (48%) a lack of appropriate follow-up support (39%) and being unable to access scans to monitor their breast cancer (35%). However, access to some types of support, including counselling, may have been difficult before the pandemic.

‘Doing clinics in a mask and telling someone they have cancer is very impersonal and not being able to maybe put a hand on their shoulder or offer proper empathy is not very nice.’
Nicky Roche, consultant breast surgeon

The face-to-face support services provided by Breast Cancer Now were suspended at the start of the pandemic, although we have been offering online alternatives for our Moving Forward programme for primary breast cancer, and Living with Secondary Breast Cancer programme, as well as opening up Our Someone Like Me service to provide one-to-one support for anyone with breast cancer feeling isolated or anxious as a result of the pandemic. We will also be rolling out personalised direct referrals to our services later this year, to ensure people are aware of the services Breast Cancer Now provides from diagnosis onwards. Our Helpline and Ask Our Nurse services continued to operate as normal.

‘Although treatment wasn’t changed, the lack of supporting services have made it very stressful. Also, I have been unable to see the oncologist which would have been a key point of reassurance.’
Survey respondent

By far the biggest change in people’s care was the move from face-to-face appointments to telephone appointments, with 82% of respondents saying they had experienced this. Whilst some preferred this as it was quicker and easier than travelling into hospital, others were concerned that they had not been seen in person. Moving forward it will be important to remember that virtual appointments will not be the right way of interacting with everyone, every time and the healthcare professionals we spoke to recognised this.

‘Just because appointments by phone are convenient for doctors, it doesn’t mean it is best for patients. We need to get back to seeing patients – not all of them – some of them, including new patients. At some stage, we all need to think about which appointments can be done appropriately by telephone and which patients need to come into hospital.’
Andreas Makris, consultant clinical oncologist
Personalised care
Everyone with cancer should have access to personalised care, including a needs assessment, care plan and health and wellbeing information. NHS England’s Long-Term Plan includes an aspiration that this will happen by 2021. The Scottish Government has committed to this happening by 2023 and made good progress by funding the Transforming Cancer Care programme with Macmillan Cancer Support to provide access to a support worker to assess patient’s needs and link with relevant support services. Actions in the Wales Cancer Delivery Plan to support the delivery of person-centred care include undertaking needs assessments and care planning. Progress towards implementing this must continue. Northern Ireland is currently developing a new cancer strategy and this should also include commitments on personalised care.

Both changes to treatment and care as a result of the coronavirus outbreak, and the emotional impact this is having on people with breast cancer make access to a clinical nurse specialist (CNS) and support services more important than ever. The cancer recovery plans being developed across the UK must ensure that patient’s care and support needs are being met during this period, alongside restoring cancer diagnostics and treatment to pre-pandemic levels. Some services, such as monitoring scans, will be using the same equipment and staff as diagnostic scans.

Access to clinical nurse specialists
Clinical nurse specialist’s (CNSs) play a crucial role in co-ordinating care and providing the information and support patients need to manage their diagnosis and treatment. Access to a CNS can make a big difference to the way people experience their care. This is particularly important for patients with secondary breast cancer who will be on lifelong treatment and have complex emotional and support needs.

However, in a Breast Cancer Now survey of secondary breast cancer patients in 2019 only 30% said they regularly saw a CNS, and only 65% said their CNS had enough time to spend with them. A Breast Cancer Now survey of CNSs in early 2020 found that only 35% felt that they have enough time to offer each secondary breast cancer patient the opportunity to discuss their wider concerns and needs in the weeks following diagnosis, and even less (31%) have the time to offer this as treatment changes or the cancer progresses.

Amongst the 446 respondents to our survey who told us they accessed support during this period, the most popular way of doing so was from a CNS (30%). However, 41% of respondents also felt they had less contact with their CNS during this period.

‘The total lack of face to face appointments has been very challenging to come to terms with. Telephone consultations didn’t answer questions and were often at unexpected times.’
Survey respondent

Being diagnosed and treated for breast cancer can be anxious and stressful at any time. Many patients told us that coronavirus had an impact on their emotional wellbeing, with 60% of all respondents to the survey feeling stressed or anxious, 58% being worried about the future, 38% feeling isolated and 35% unable to plan for the future.

‘I have really noticed the impact of the current situation on patient’s emotional wellbeing which is really difficult. Patients may be out in the community and may not be supported in the same way they usually are or it may have exacerbated previous issues.’
Mark Beresford, clinical oncologist

41% OF RESPONDENTS FELT THEY HAD LESS CONTACT WITH THEIR CNS DURING THIS PERIOD
The cancer recovery plans being developed by governments and the NHS across the UK must ensure that the care and support needs of patients are met during this period.

The upcoming Comprehensive Spending Review must provide the necessary additional funding to recruit and train more clinical nurse specialists to ensure that everyone with breast cancer—including those with secondary breast cancer—is supported by a CNS.

Progress towards ensuring that everyone with breast cancer has personalised care must continue, and commitments on this should be included in the new cancer strategy being developed in Northern Ireland.

Care plans should be reconsidered where necessary to take account of changes to people’s treatment during the pandemic.

If patients are advised to shield again then the shielding programme should ensure patients are signposted to relevant emotional, practical and financial support services.

WHAT NEEDS TO HAPPEN NOW?

The cancer recovery plans being developed by governments and the NHS across the UK must ensure that the care and support needs of patients are met during this period.

The upcoming Comprehensive Spending Review must provide the necessary additional funding to recruit and train more clinical nurse specialists to ensure that everyone with breast cancer—including those with secondary breast cancer—is supported by a CNS.

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Care plans should be reconsidered where necessary to take account of changes to people’s treatment during the pandemic.

If patients are advised to shield again then the shielding programme should ensure patients are signposted to relevant emotional, practical and financial support services.

BCNs [breast care nurses] are a critical point of contact....I was lucky my treatment continued, but it shouldn’t be forgotten that support is still needed for those who are still undergoing treatment.’

Survey respondent

There was already a shortage of CNSs before the pandemic. Our survey of CNSs found that only one in three believed their hospital had enough specialist nurses to give secondary breast cancer patients the support and care they need, with 82% saying this was because there are not enough nursing posts. In common with other parts of the workforce, many CNSs were redeployed elsewhere in the NHS during the peak of the pandemic. For example, over 400 Macmillan NHS professionals including Macmillan funded CNSs were redeployed.39

The recent NHS People Plan for 2020/21 in England included 350 training grants for nurses to become cancer CNSs and chemotherapy nurses.50 However, additional funding is needed to recruit and train more CNSs to meet the needs of people living with breast cancer across the UK, now and in the future. The upcoming Comprehensive Spending Review must provide this funding.

Shielding

In March people who were identified by their clinical team as extremely clinically vulnerable were advised to ‘shield’. Those with breast cancer having treatment that suppresses the immune system were likely to be advised to shield. Just over half of respondents to our survey (52%) were advised to shield.

Over the course of the pandemic guidance on shielding has varied across the nations, with each lifting shielding gradually. In August the shielding programme was paused across the UK as a result of the decrease in coronavirus cases. However, nearly two thirds (65%) of respondents who were advised to shield were concerned about this decision.
CONCLUSION
Coronavirus has affected every part of the breast cancer pathway.

What we have seen and heard about the impact of coronavirus on breast cancer, including through our survey and discussions with healthcare professionals, suggests there are many challenges that need to be addressed moving forward.

These include: ensuring that there are clear plans in place to safely manage the likely surge of demand for diagnostics and imaging as referrals continue to recover and breast screening restarts; that treatments are safely restored to pre-pandemic levels and demand dealt with; that progress in breast cancer research, including through clinical trials, does not stall; and that patients have the care and support they need at this time.

The pandemic has resulted in some positive changes. The NHS moved quickly to issue guidance on safely diagnosing and treating cancer. Some changes to drug treatment and radiotherapy — which benefit both patients and the NHS — were implemented more quickly than they would otherwise have been. And for some patients, virtual consultations have freed up time and removed the anxiety of going to hospital during this period. We need to make sure that these positive changes are carried forward.

The recommendations that we have made seek to address the challenges that have arisen and ensure the most is made of the positive changes, as well as helping to ensure that we are well prepared for any further peaks of coronavirus.

Coronavirus has placed huge additional strain on people affected by breast cancer. With more challenges ahead, we must act now to ensure that breast cancer services do not have to be paused again.
Diagnosis
The NHS across the UK should continue to encourage people who have symptoms that might be cancer to contact their GP surgery to get them checked out.

Governments and the NHS across the UK must assess diagnostic capacity across breast cancer services and set out a demand-led, long-term plan to ensure the workforce has enough resource and support now and in the future.

If open invites are used for the breast screening programme, uptake – including amongst groups already less likely to access breast screening – must be monitored regularly and locally, and measures to mitigate against a decline in uptake implemented. They should also be used for a limited period, as proposed.

Overarching
The recovery plans for cancer being developed by governments and the NHS across the UK must set out:

- how the expected influx of demand for imaging and diagnostics will be safely managed;
- set out how treatment will be safely restored to pre-pandemic levels, and the backlog dealt with. This includes women who were unable to have breast reconstruction during this time, who should not be prevented from having these operations as a result of any time limits imposed on them by CCGs in England;
- identify and address the needs of secondary breast cancer patients, including recognising the importance of drug treatment for these patients; and
- ensure that the care and support needs of patients are met during this period.

The UK Government must take immediate action as part of the upcoming Comprehensive Spending Review to provide:

- much-needed investment for recruitment in the imaging and diagnostic cancer workforce.
- the necessary additional funding to recruit and train more clinical nurse specialists to ensure that everyone with breast cancer – including those with secondary breast cancer – is supported by a CNS.
- match funding for future charity research over the next three years via a Life Sciences-Charity Partnership Fund for medical research charities.

SUMMARY OF RECOMMENDATIONS
‘THE NHS ACROSS THE UK SHOULD CONTINUE TO ENCOURAGE PEOPLE WHO HAVE SYMPTOMS THAT MIGHT BE CANCER TO CONTACT THEIR GP SURGERY TO GET THEM CHECKED OUT.’

**Treatment and clinical trials**

Some treatment changes introduced during the pandemic, including the reduction in the number of doses of radiotherapy and cycles of adjuvant trastuzumab, have benefits for patients and the NHS and should be enabled to continue with these.

The NIHR and equivalent bodies in the nations should continue to closely monitor the restart of clinical trials and publish information on them, and consider if, and what, further measures could be taken to assist with this.

The NIHR and MHRA should consider how the speed with which clinical trials for vaccines and treatments for coronavirus have been set up could be applied to cancer trials.

**Care and Support**

Progress towards ensuring that everyone with breast cancer has personalised care must continue, and commitments on this should be included in the new cancer strategy being developed in Northern Ireland. Care plans should be reconsidered where necessary to take account of changes to people’s treatment during the pandemic.

If patients are advised to shield again then the shielding programme should ensure patients are signposted to relevant emotional, practical and financial support services.


6. Estimate based on cancer waiting times data in England and Wales. For Scotland and Northern Ireland the average percentage drop in referrals in England between March and July 2020 was applied to referrals between March and July 2019.


21. Estimate based on data from the Audit on the number of women having immediate and delayed reconstruction and updated to 2020.


24. We asked respondents that were receiving or awaiting surgery how much they agreed or disagreed with a set of statements about changes to their surgery. Those who said that the statement was not applicable to them were excluded from this analysis.

25. Ibid.
We asked respondents that were receiving or awaiting drug treatment how much they agreed or disagreed with a set of statements about their care during the pandemic. Those who said that the statement was not applicable to them were excluded from this analysis.


Earl, Prof HM et al, 6 versus 12 months of adjuvant trastuzumab for HER2-positive early breast cancer (PERSEPHONE); 4-year disease-free survival results of a randomized phase 3 non-inferiority trial, The Lancet, June 2019. Available at: doi.org/10.1016/S0140-6736(19)30650-6.


We asked respondents that were receiving or awaiting radiotherapy how much they agreed or disagreed with a set of statements about changes to their radiotherapy. Those who said that the statement was not applicable to them were excluded from this analysis.


Impact of COVID19 on UK Radiotherapy, Action Radiotherapy. Available at: eb9f9be9c-890d-4dca-b67e-2c40c584e61d/filesuser.com/ugd/b88571_5a27d1bd9d434e88bab9fac3199de2e8.pdf

Data provided by NHS England and NHS Improvement.

We asked respondents that were receiving or awaiting radiotherapy how much they agreed or disagreed with a set of statements about changes to their radiotherapy. Those who said that the statement was not applicable to them were excluded from this analysis.

DHSC issues guidance on the impact of COVID-19 on research funded or supported by NIHR, National Institute for Health Research, March 2020. Available at: www.nihr.ac.uk/news/dhsc-issues-guidance-on-the-impact-of-covid-19-on-research-funded-or-supported-by-nihr/24469


Answer to UK parliamentary question provided by Helen Whately MP on 18 June 2020.

A framework for restarting NIHR research activities which have been paused due to COVID-19, National Institute for Health Research, May 2020 Available at: www.nihr.ac.uk/documents/ restart-framework/24886


We asked respondents how much they agreed or disagreed with a set of statements about their care during the pandemic. Those who said that the statement was not applicable to them were excluded from this analysis.

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The Unsurvivors, Breast Cancer Now, October 2019. Available at: breastcancernow.org/sites/default/files/bcn_report1_1019v2_.-_final_22.11.19_.pdf

We asked respondents how much they agreed or disagreed with a set of statements about their care during the pandemic. Those who said that the statement was not applicable to them were excluded from this analysis.

Written evidence submitted by Macmillan Cancer Support for Health and Social Care Committee's inquiry on Delivering Core NHS and Care Services during the Pandemic and Beyond, Macmillan Cancer Support. Available at: committees.parliament.uk/writtenevidence/4582/pdf/

DON'T FORGET

We’re here if you ever need to talk.

Our breast care nurses and highly trained staff on our free Helpline are here for you, whatever you’re going through.

We’re ready to listen on 0808 800 6000 or you can find information and support online at breastcancernow.org