Policy Report

Daiichi-Sankyo

Passion for Innovation.
Compassion for Patients.™

A COVID-19 recovery and service delivery plan for secondary (metastatic) breast cancer

DSC/21/0212 October 2021

Contents

This event was initiated and funded by Daiichi Sankyo. The report was funded by Daiichi Sankyo and co-produced with a group of stakeholders who attended the roundtable on 4 May 2021.

DSC/21/0212 October 2021

Executive summary

As we gradually emerge from the COVID-19 pandemic against the backdrop of the Cancer Recovery Plan[i] in which the NHS sets out proposals to return essential cancer services to pre-COVID-19 levels, there is an urgent need to ensure that secondary (metastatic) breast cancer is not forgotten in local and national recovery initiatives.

Before the pandemic, a perception already existed among the patient and clinical community that the time, effort and funding devoted to secondary breast cancer was not proportionate to the numbers of people it affects.[ii, iii]

On 4 May 2021, Daiichi Sankyo UK facilitated a roundtable of policymakers, clinical experts, healthcare professionals and patient advocates to discuss the impact of COVID-19 on secondary breast cancer care. Participants sought to understand where the disease fits into local cancer recovery plans and the broader work of the Cancer Recovery Taskforce.

The roundtable discussion was chaired by Craig Tracey MP, Chair of the All-Party Parliamentary Group (APPG) on Breast Cancer. A group of roundtable participants then co-created this report, which provides a collective action tool with principles of reform and recovery for patient groups, industry, NHS England and Cancer Alliances.

On 19 May 2021, NHS England announced funding for a national secondary breast cancer audit. In a statement on behalf of the APPG on Breast Cancer[iv], Craig Tracey MP welcomed the news:

> *"The APPGBC has been calling for improvements to the care of people living with secondary breast cancer for many years now and highlighted the need for an audit that provides accurate data on those diagnosed and living with the disease to help make this a reality."*

This long-anticipated announcement provides the baseline for any set of recommendations around secondary breast cancer recovery. During the discussion, patients called for action and accountability on data collection and clinicians were clear that a return to the level and quality of service provided pre-COVID was unacceptable. Participants felt that we must 'build back better' to provide a better quality of life and the best chance of survival to the estimated 35,000 people in the UK living with secondary breast cancer.[iii]

The current deficit in data collection means there is uncertainty around the actual numbers of secondary breast cancer patients. Lack of accurate and easily accessible data makes it difficult for commissioners and providers to understand their local patient populations and how to plan services.

Despite a mandatory requirement for data to be collected by NHS hospital trusts since 2013, there are systemic barriers to data collection in this area, including workforce shortages, confusion over the definition of secondary breast cancer and lack of buy-in and leadership.[v] The situation is similar in other healthcare systems in the UK.

As the Healthcare Quality Improvement Partnership (HQIP) begins the process of scoping and commissioning the secondary breast cancer audit, it must employ learning from the world-class audits already established in breast cancer, including the management of screen-detected cancer and the HQIP audit of the management of breast cancer in older patients.

There must also be clear, accountable leadership to ensure the right data is collected and made available with a real sense of urgency. This will not only enable services to get back on track but enable transformational change for the lives of people living with secondary breast cancer and their families.

Key themes from the discussion

The roundtable plenary discussion focused on three main questions and the themes which emerged are presented under these headings:

1. How do we ensure secondary breast cancer is seen as a priority in wider local cancer recovery plans?

- We now have a national cancer crisis as a result of the pandemic and must not underestimate the scale of the challenge in terms of clearing the backlog of diagnosis, treatment and care.[vi]

- Secondary breast cancer must not be forgotten in national and local cancer recovery plans. Patients and clinicians are clear that we cannot simply return to the level of service available pre-COVID. There should be a review of national cancer standards for secondary breast cancer care, including the effectiveness of existing targets for diagnostic and treatment waiting times. The potential effectiveness of patient-reported outcome measures should also be considered.

- More work is needed on assessing and understanding appropriate levels of clinic staffing, including how resource allocation can best fit local needs and demands. At present, service funding is determined by the number of new patients entering the system. As secondary breast cancer patients live longer, services become increasingly underresourced.

- There were calls for action and accountability from NHS Trusts on secondary breast cancer data collection and reporting, whilst acknowledging the complexity and variation in IT platforms and databases used in different areas.

- A standard template business case would enable breast cancer services to make the case to their Trust or Cancer Alliance for secondary breast cancer nurses, which would lead to direct service improvements. These should reference the nursing policy commitment in the NHS Long Term Plan and the workforce innovations proposed in the National Cancer Services Recovery Plan[i] (e.g. training grants for clinical nurse specialists and chemotherapy nurses, flexible working innovations and nurses working at the top of their licence by deploying an effective skill mix model).

2. What can we learn from new ways of working implemented during the pandemic?

- Learning from existing patient information resources and new innovations, such as Greater Manchester Cancer's pilot of the 'red flag infographic', created by After Breast Cancer Diagnosis (ABCD)[vii] in post-treatment summaries for primary breast cancer. These combined resources should be evaluated with a view to developing a national resource to increase awareness of secondary breast cancer signs and symptoms.

- There would be value in conducting research into the use of remote consultations for secondary breast cancer patients across all aspects of the care pathway. Patients should continue to be offered a choice of remote or face-to-face consultations (including video consultations where available).

- During the pandemic, clinical trial processes were faster, bureaucracy was minimised, there was rapid approval of protocol amendments and trials quickly moved through each stage. Data was also collected quickly and accurately across the UK. Key lessons should be incorporated across the following areas:

    - Reviewing how to improve eligibility criteria for trials in secondary breast cancer.
    - Leveraging the potential of genomic biomarkers to base trial cohorts on tumour mutations.
    - Design trials to reflect real world data, and address inequalities in patient access.
    - Evaluate the clinical utility of cancer genomic testing for advanced breast cancer as well as rare cancers.

- Lessons should be learnt and adopted from pilots and projects, which have utilised the roles of experienced nursing professionals to raise awareness of research, trials, and genomics amongst secondary breast cancer patients. This should lead to the development of a comprehensive database of clinical trials.

3. What role can data and audit play in reinstating and improving secondary breast cancer care?

– Data collection is the bedrock of any future service improvements for patients and clinicians in this area. The national secondary breast cancer audit, funded by NHS England, should:

  - Consider the potential role of patient-reported outcome measures.
  - Put in place mechanisms for interim reporting as a milestone towards developing the future rollout of the audit.
  - Build on DATA-CAN's work to gather feedback on chemotherapy attendances across England to provide a starting point to examine the percentage of patients with metastatic disease in treatment.[viii]

– In the longer term, the outputs of the national secondary breast cancer audit should be used alongside other analytical service planning approaches to inform the following priorities:

  - Differences and gaps in service provision, service quality and allocation of secondary breast cancer Clinical Nurse Specialists across England. For example, Macmillan Cancer Support's figures show that pre-pandemic, the NHS had less than half the cancer Clinical Nurse Specialists it needed[ix] which led to calls for investment in the secondary breast cancer workforce via the Comprehensive Spending Review.
  - Workforce modelling to better support resource allocation for the secondary breast cancer workforce. There was recognition that the secondary breast cancer specialist workforce was already insufficient and ill-defined pre-pandemic, and the current workforce is at breaking point, suffering exhaustion and low morale. New approaches for secondary breast cancer workforce management could include the deployment of cancer staff returning to the NHS through the' bringing back staff programme' as well as meeting the ambitions of the NHS People Plan.
  - Further research efforts into specific breast cancer types and areas of unmet need.
  - Current approaches to service funding, which do not reflect the numbers of secondary breast cancer patients currently in the system. The audit could be crucial to understanding this. Secondary breast cancer patients are living longer and staying in the system longer, especially those with ER positive and HER2 positive breast cancer, who are now considered to have a chronic disease.
  - Patient pathway design; services are not currently designed to allow for the levels of administration and increased number of hospital interactions per patient that modern treatment pathways require. Treatments that keep patients alive longer have more side effects and require significantly more staffing resources to deliver. There were calls for levels of funding to be linked to these resource-intensive treatment pathways.

A COVID-19 recovery and service delivery plan for secondary (metastatic) breast cancer; Policy Recommendations

The following recommendations are intended to provide specific, implementable collective action tools for stakeholders across the healthcare system to work towards the delivery of a better form of service delivery in this area.

1. Explore the possibility of leveraging the resources of biobanks, cancer registries and harnessing DATA-CAN's networks to provide a template for the anticipated secondary breast cancer audit, showcasing the scope and aims of the audit. This could be carried out as a collaboration between industry, patient groups and the clinical community and piloted in selected larger units.

2. Build upon work already carried out by DATA-CAN on numbers of chemotherapy attendances across England. Although this dataset does not cover newly diagnosed secondary breast cancer patients, it would provide a basis for examining the percentage of patients with metastatic disease currently in treatment.

3. The Cancer Services Recovery Plan and Taskforce have now officially ended, and recovery planning has been devolved to local systems. It is essential for Trusts and Cancer Alliances to ensure that patients with secondary breast cancer are not left behind as the backlog of diagnosis, treatment and care is cleared. Local systems must establish specific priorities for secondary breast cancer services and workforce that are based on the number of secondary patients currently in their services and the complex, resource-intensive care pathways these patients follow (accepting that this number will be an estimate pre-audit).

4. Local recovery plans should build on learning from the increased use of remote consultations and continue to offer a choice of remote or face-to-face interactions where appropriate.

5. Support Macmillan Cancer Care's call for the Government to urgently guarantee the investment needed to grow and support the cancer workforce via the Comprehensive Spending Review in Autumn 2021 by providing a fully funded NHS People Plan. Sufficient numbers of secondary breast cancer Clinical Nurse Specialists and other specialist staff are vital to offering a streamlined service, personalised care and supporting health systems to collect and report on numbers of secondary breast cancer patients.

6. Support the promotion and uptake of education modules on signs, symptoms, referral pathways and treatment of secondary breast cancer to primary care practitioners through the online primary care cancer education resource, Gateway C.

7. Build upon the launch of the Gateway C training on breast cancer recurrence, supporting Breast Cancer Now's work to increase awareness of the signs and symptoms of secondary breast cancer and ensure that learning is shared widely from the use of the ABCD Red Flag Infographic aimed at patients who have completed primary breast cancer treatment.

8. Facilitate a cross-sector conversation, involving patients, industry, the NHS and Genomics England (as part of the Genome UK implementation plan)[x], using secondary breast cancer as an example, on:

   - Eligibility criteria for trials, how trials can reflect real-word data and patient-reported outcomes.
   - Use of genomic biomarkers to base trial cohorts on tumour mutations.
   - Whether broad cancer genomic testing should become the standard of care for secondary breast cancer.
   - The cost-effectiveness of these approaches for the NHS and benefits for industry.
   - Using the Make 2nds Count Patient Trials Advocacy project as a case study to test some of these ideas.[xi]

9. Create a mandate for all secondary breast cancer cases to be discussed at a multidisciplinary team (MDT) meeting and ensure this is monitored by the Care Quality Commission. The MDT should include Clinical Nurse Specialists who meet the professional competencies for secondary breast cancer set out by the Royal College of Nursing in 'A Competency Framework for Nurses Providing Care to People with Breast Cancer.'[xii]

Roundtable participants

The roundtable plenary discussion focused on three main questions and the themes which emerged are presented under these headings:

Name	Role & Organisation
Craig Tracey (Chair)	Member of Parliament for North Warwickshire since 2015. Shortly after his election, Mr Tracey was asked to co-chair the All-Party Parliamentary Group (APPG) for Breast Cancer, having spent many years as a fundraiser for the disease.
Dr Anne Armstrong	Consultant in Medical Oncology and Honorary Senior Lecturer, The Christie.
Ms Clare Garnsey	Clinical Lead for Breast Cancer at Greater Manchester Cancer Alliance and Consultant Oncoplastic Breast Surgeon, Bolton NHS Trust.
Andy McGuinness	Senior Public Affairs Adviser, Macmillan Cancer Support.
Claire Goldrick	Pathway Manager for Breast, Genomics, HPB, SCMG at Greater Manchester Cancer Alliance.
Ethna McFerran	Research Fellow and Cancer Health Economist at Queen's University Belfast and Royal College of Nursing Breast Cancer Forum member.
Jo Taylor	Founder of METUPUK, a patient advocacy group for secondary breast cancer. Jo lobbies for progress on secondary breast cancer and lives with the disease herself.
Lesley Stephen	Lesley Stephen was diagnosed 'de novo' with secondary breast cancer in 2014. She is an active patient advocate, working with a range of organisations including NCRI, Breast Cancer Now METUPUK and Make 2nds Count.
Mia Rosenblatt	Associate Director of Policy and Campaigns, Breast Cancer Now. **Breast Cancer Now supported the event with a presentation and input to the discussion but did not participate in drafting this report.**
Miss Julie Doughty	President of the Association of Breast Surgery and consultant breast surgeon at Gartnavel General Hospital in Glasgow.

About Daiichi Sankyo UK

Daiichi Sankyo UK Ltd is a UK affiliate company with corporate origins in Japan. We create and supply innovative products to help the NHS to deliver better patient care in the fields of cardiovascular disease and oncology.

Our company was founded in 2006 through the merger of Japanese companies Daiichi and Sankyo in Europe. With a rich legacy of scientific expertise dating back more than 100 years, we are a pioneer behind leading pharmaceuticals that have contributed to the improvement of many lives across the world.

Our mission is to contribute to the enrichment of quality of life through the discovery and delivery of innovative medicines that address diverse and unmet medical needs.

We are committed to providing innovation that demonstrates value and supports the NHS in its delivery of sustainable high-quality care, enabling efforts to reduce health inequalities and unwarranted variations and which puts the patient at the heart of the service.

For more information, please contact:

Alistair Gordon,
Government Affairs
and Corporate
Communications Manager,
Daiichi Sankyo UK Ltd.
Mobile +44 7591953681
Alistair.Gordon
@daiichi-sankyo.co.uk

References

[i] NHS Cancer Programme. Cancer Services Recovery Plan, 14 December 2020,
https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/12/C0821-COVID-19-Cancer-services-recovery-plan-14-December-2020.pdf
(accessed August 2021)

[ii] METUPUK, https://metupuk.org.uk/about-us/why-are-we-doing-this (accessed August 2021)

[iii] Breast Cancer Now, 'Until things Change: Unsurvivors' October 2019.
https://breastcancernow.org/sites/default/files/bcn_untilthingschange_final_30.09.20.pdf
(accessed August 2021)

[iv] Breast Cancer Now, Statement from the APPGBC on a National Secondary Breast Cancer Audit, 19 May 2021
https://breastcancernow.org/get-involved/campaign-us/all-party-parliamentary-group-breast-cancer/news-events
(accessed August 2021)

[v] Breast Cancer Care, Secondary, Not Second Rate, the case for change summary report, October 2017
https://breastcancernow.org/sites/default/files/the_case_for_change_summary_report.pdf
(accessed August 2021)

[vi] Macmillan Cancer Support, The Forgotten C. The impact of Covid-19 on cancer care, October 2020,
https://www.macmillan.org.uk/assets/forgotten-c-impact-of-covid-19-on-cancer-care.pdf
(accessed August 2021)

[vii] Greater Manchester Cancer, Hello my name is… Jo Taylor,
Service User Representative on GM Cancer Breast Pathway Board, October 2020
https://gmcancer.org.uk/joetaylorblog
(accessed August 2021)

[viii] Lai G.A ,Pasea L, Banerjee A, et al, Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study, BMJ Open 2020;10:e043828. doi:10.1136/bmjopen-2020-043828
https://bmjopen.bmj.com/content/10/11/e043828.info
(accessed August 2021)

[ix] Macmillan Cancer Support, Addressing the Gap-Highlighting the need for growing the specialist cancer nursing workforce, September 2020.
https://www.macmillan.org.uk/_images/addressing-the-gap-report_tcm9-358808.pdf
(accessed August 2021)

[x] Department of Health and Social Care, Department for Business, Energy & Industrial Strategy, Office for Life Sciences, and Lord Bethell of Romford, Genome UK: the future of healthcare, 26 September 2020
https://www.gov.uk/government/publications/genome-uk-the-future-of-healthcare
(accessed August 2021)

[xi] Make 2nds Count, Make 2nds Count Trial Patient Advocate Service
https://www.make2ndscount.co.uk/funding-research/patient-trials-advocate
(accessed August 2021)

[xii] Royal College of Nursing, A Competency Framework for Nurses Providing Care to People with Breast Cancer.
https://breastcancernow.org/sites/default/files/rcn_framework.pdf
(accessed August 2021)