



APPG on Breast Cancer Roundtable on a Secondary Breast Cancer Audit

Minutes

10-11am, Thursday 4 February 2020

Chaired by Craig Tracey MP, Co-Chair of the APPG on Breast Cancer

Virtual meeting

Speakers and attendees

1. **Claire Myerson**, Patient Advocate
2. **Dr Andreas Makris**, Consultant Clinical Oncologist, Mount Vernon Cancer Centre. Co-Chair of the UK Breast Cancer Group (UKBCG)
3. **Professor Mark Beresford**, Consultant Oncologist and Clinical Lead for Oncology and Haematology, Royal United Hospital Bath. Co-Chair of the UKBCG
4. **Dr Caroline Wilson**, Medical Oncology Consultant and Honorary Clinical Senior Lecturer, University of Sheffield
5. **Prof Carlo Palmieri**, Professor of Translational Oncology & Medical Oncologist Molecular and Clinical Cancer Medicine, The Clatterbridge Cancer Centre
6. **Amir Nawaz**, Associate Medical Adviser, Novartis
7. **Dr Ruhe Chowdhury**, Acting Medical Director Oncology, Pfizer UK
8. **Dr David Montgomery**, Oncology Medical Director, Daiichi Sankyo
9. **Emma Lavelle**, Policy Manager, Breast Cancer Now
10. **Steve Brine MP**
11. **Liz Twist MP**
12. **Rosie Cooper MP**
13. **Debbie Abrahams MP**
14. **Hattie Turner, David Johnston MP's office**

Minutes

1. Introduction

Craig Tracey MP

- Introduced the speakers and welcomed the MPs present.
- Raised how secondary breast cancer has been a priority issue for the APPGBC for many years. The APPGBC 2018 report on Geographical Inequalities in Breast Cancer showed that, while breast cancer outcomes were good and improving compared to other cancers, that was masking stark geographical inequalities and variation in the support women with secondary breast cancer receive.
- Said that we need to address this variation, but we cannot do that while we do not have consistent data collection.
- Highlighted how in 2015 he chaired a debate on secondary breast cancer, where he highlighted, among other things, the practical barriers to data collection. Said that last year he chaired another debate and brought up the same issues again, noting his disappointment with how little things had progressed. He shared that in that debate, the Minister made a commitment to work with him on a secondary audit, and it is because of that that the APPGBC organised the roundtable.
- He said he wants to hear from a wide range of experiences and perspectives on why a secondary breast cancer audit is needed and how should it be conducted.

All the evidence received will be shared with the Department of Health and Social Care and NHS England.

2. Q&A with Speakers

- a. **Briefly, what do you view as the main benefits to improving data collection on secondary breast cancer to your work/experience? Whether there are challenges you have faced due to a lack of data and/or opportunities that could be seized with it.**
- b. **What would you recommend as priorities to be included in a secondary breast cancer audit?**

Claire Myerson

- Shared her frustration over the lack of progress. Said patients with secondary breast cancer do not have time to wait for long overdue improvements.
- Said the treatment she is on is the last licenced drug in the UK she can try. Her best hope is that she lives long enough for another treatment to be licenced.
- Highlighted that a lot of people do not understand what secondary breast cancer is and that the prognosis is still not great. The perception is that breast cancer in the UK is fixed.
- Shared that she gave a speech in 2015 in Parliament highlighting the need for better data collection on secondary breast cancer patients. In 2016, she attended the Tory and Labour party conferences. In March 2020, she was part of a group who met with the Minister Jo Churchill MP and delivered a petition signed by 71,000 people calling for improvements. It has been almost one year on from the petition and sadly a clear commitment has not been made to fund a national audit on secondary breast cancer. She hopes this will change now.
- Shared the key issues she and other secondary breast cancer patients face, from the lack of access to clinical nurse specialists and delays in diagnosis, all streaming back from the fact that health services do not know how many people are living with secondary breast cancer. Data enables commissioners and healthcare providers to better understand their local patient populations and plan for this.
- Said that 'perfect is the enemy of good' and that we just need to start. That the first stop is data collection, and everything else will go from there.

Dr Makris

- Said that progress has been made but much more needs to be done.
- Raised equity of access to treatment as a core issue. Said geographical variations still exist and that an audit can tell us this and what we need to address and prioritise. Reminded that this is a core principle for the NHS. Also said that this is the biggest improvement that can be made to breast cancer, bringing everyone everywhere up to the best level. Said that we need to do an audit to tell us what the state in the country is and then allow us to implement changes.
- Highlighted that most audits now are in early breast cancer, which have led to improvement, so the same could be replicated for secondary breast cancer.
- Said that with these types of audits there is always a balance to be struck between getting results quickly or getting more comprehensive data but waiting much longer. He believes NHS England should aim to start the audit very soon after COVID has significantly subsided, still in 2021.
- Said that the key to high quality metastatic breast cancer care is to get patients diagnosed as quickly as possible and in front of an oncologist who can then deliver the best possible drugs available. He thought the audit could help to show

variations and that we should remember that some centres might be good for some aspects of care but not all and therefore we need to be aware of that issue.

- His priorities would be to look at access to clinical nurse specialists, palliative care services, and clinical trials. He said that nurses do not exist everywhere and that access to nurses who had some level of specialisation in metastatic disease alongside access to clinical trials was key. He also felt that access to psychologists, social workers, palliative care, and hospice services should be looked at as this makes a huge difference to quality of life for patients.
- Also raised the importance of looking at how Multidisciplinary Teams work. He felt it was extremely important for oncologists to have the opportunity to discuss more complex cases together rather than discuss patients in a huge multidisciplinary team meeting that involves a host of other professionals that would not be interested in the finer points of complex drug management.

Professor Beresford

- Said improved data on secondary breast cancer patients would help clinicians make the business case for more resources for these patients, such as hiring clinical nurse specialists.
- He used the example of the cardiologist who recently came to his board with a business case for more resources, including more consultants and nurses, because of the introduction of a new treatment for coronary heart disease. He drew the parallel with metastatic breast cancer where the introduction of new treatments like CDK 4/6 inhibitors have created a huge additional burden on the system, but the clinicians have not made a strong business case for additional resources, and just carried on making ends meet.
- Overall, said an audit will help provide evidence of disparity across the country. It will also help make the business case for the increase in capacity that will be needed to cope with what is coming down the track in terms of new treatments and increased demand.
- Said the way specialists have developed in most hospitals has been very diagnostic based. They spend a lot of time with early breast cancer, managing outcomes of surgery, and have not been focused on secondary breast cancer.
- Made the case for administrative support for clinicians to support with data collection and ensure the right data is collected.
- Also made the case for improving access to clinical trials, the need to be more focused about getting patients into regional studies and having a better view about which studies are going on across the country.
- He was very supportive of a secondary breast cancer audit and was keen that the UK Breast Cancer Group (UKBCG) group be involved.

Professor Palmieri

- Started by saying that secondary breast cancer patients feel ignored. Their needs unaddressed and that all the focus is on primary breast cancer. Said that we count the deaths but not the living.
- Shared the 2012 NCIN report, where then Prime Minister David Cameron agreed with the need for an audit and asked what has happened since. He said we were back in the same place discussing the same issue and hoped that the roundtable led to something happening for once.
- He is very supportive of the idea of an audit generally and feels that much more needs to be done to recognise the needs of women with metastatic breast cancer.
- Shared that he recently reviewed his data from Clatterbridge and was surprised to find over double the number of women living with secondary breast cancer than he was expecting. Counting the patients helped him make the case for clinical nurse specialists.

- Raised the importance of benchmarking quality of care and that we will know the kind of care we are providing in this country with an audit.
- He felt that there was significant benefit to having rich data collected about patients with metastatic disease as this would encourage research to come to the UK and keep us competitive with others in Europe who are developing this kind of data.
- He thought it would be very interesting to be clear about how many are diagnosed and if they experience delays following exhibiting red flag symptoms.
- He felt that it would be good too to measure against the internationally recognised standards such as ESMO and ASCO and to be able to demonstrate survival according to variations UK wide or by phenotype.

Dr Wilson

- Said an audit is necessary and shared that in Sheffield she has no access to secondary breast cancer data. Said they are still not counting how many patients are in her area, despite being mandatory.
- Talked about the need of getting real world data on prescribing practices. Wanted to see efficacy and toxicity of treatments. Want to be able to see how many patients we have according to receptor status and how effective the treatments are by collecting information on rates of progression on treatment.
- Said she thinks the role of data collection needs commissioning and implementing in all NHS trusts and that it would be fantastic to aid local and national audit and research.
- Highlighted the need for administrative support to collect this data and that upfront investment would be needed.

Amir Nawaz (Novartis)

- Raised the importance of having real-world data to establish a baseline, highlighting the benefits of an audit to industry.
- Said an audit would provide data to support Health Technology Assessments (HTAs) For example, how new treatments would fit in to treatment pathways, help identify current standard of care, outcomes, unmet needs, burden of need.
- Said that in breast cancer, the data we receive from sales is very limited, while it may show us the uptake of a treatment and its geographical use, it does not provide an understanding around which patients the treatment is being used in, or in which line of treatment. The data that is available from the NHS (Cancer Outcomes and Services Dataset – COSD, Systemic Anti-Cancer Therapy Dataset - SACT) also has several limitations, and very often there are gaps / missing information in these data sets. For example, the NHS data sets often do not contain detailed patient characteristics (such as co-morbidities), or information on mutational status, adverse events (AEs), or reason for discontinuation of treatment. Another limiting factor is the lack of consistency in the data that is captured, leading to difficulties in merging data sets from different places. We know that there are better examples out there – if we compare what is available to the National Lung Cancer Registry, for example, the level and consistency of data capture in breast cancer is poor.
- Said it is important to capture the data better and more consistently. It is about being able to better utilise a robust data set in focused areas of interest versus lots of data in a scattershot approach. Some of the focused areas that would be of particular interest to them would include:
 - Data to support differentiation of treatment pathways, including data around patient outcomes, progression, and survival in a real-world setting.
 - Real world safety - frequency of dose reductions/interruptions/withdrawals and related AEs, relative dose intensity, impact of AEs on quality of life.

- Treatment landscape - understanding the lines of therapies of patients and % of relapse.

Dr Chowdhury (Pfizer UK)

- Said that we do not know the baseline, do not know what happens in the real world. Said they are currently applying clinical trials data to general population and not using real-world data, which is a problem as clinical trials recruitment is very specific and often excludes older patients, ethnic minorities, and certain geographical areas. Said they need the audit to do the best for their patients.
- Said that we need to be in a position where we can say effectively that the drugs we are giving to our patients are the right medicine at the right time. We know breast cancer is a heterogenous cancer. By not seeing what is happening to our patients we are doing these patients a disservice.
- Said doing an audit on a national level would be far more cost effective.
- Said that changes in the way NICE will conduct assessments mean that if we do not collect this data, we will not be able to fulfil NICE data needs for new drug approvals within 2 years.
- Said we are not feeding back into loop. The CDF's purpose is to collect real-world data to see if drug is effective but said we are not doing that, just feeding back CT (core) data.

Dr Montgomery (Daiichi Sankyo)

- Shared how in the past he has asked for a list of patients with secondary breast cancer, and he could not get one. He tried to tackle major questions of how we improve the care for people with cancer, but all too often was unable to answer the question of where they were.
- Said industry is potentially willing to pay for an audit, which would help ensure access to treatments for patients now and in the future. Said Clinical Trials are going to become increasingly challenging as we are going to see increasingly small patient populations. This is going to make it hard for new drugs to get through NICE and we need to be able to provide industry with answers that allow us to get to that market industry.
- Said an audit would give the industry the information to unlock Britain's potential in this area. There is a point now post Brexit with the Medicines and Healthcare products Regulatory Agency (MHRA) set to become regulatory force on its own. Said data is needed to help unlock UK's potential as powerhouse for clinical development and research into the future.
- For research-driven companies, access to high quality, well-curated longitudinal data on secondary breast cancer benefits clinical trial study design and helps to translate trial outcomes into real-world settings. As a company moving into the oncology area, access to better data on secondary breast cancer, beyond just diagnosis, would be of significant value.
- Data on when an actual UK patient receives a medicine, how long they are treated for and what line of therapy would be particularly valuable. Volumes data would also be welcomed; this would assist efforts in attempting to understand competitor market shares and trying to assess commercial assumptions on what uptake could realistically be.
- Moreover, better data collection could also help us to gauge the actual market size in terms of patient numbers that could benefit from a new therapy. This would be great for planning/supply chain purposes amongst other things (like volume/pricing discussions). Full prescription data (by indication if possible) which is accessible and reported across the devolved nations, would also be useful for understanding the treatment landscape and trends for a disease.

- From a health system perspective, the lack of regular, accurate and accessible data makes it difficult for commissioners and healthcare providers to understand their local patient populations. Robust data collection is therefore essential to understand what the needs of patients are, how to plan and commission services.
- From Daiichi Sankyo's point of view, better data collection is important for several scientific and commercial reasons. At a commercial level, well-curated data on treatment and outcomes would help with improving assumptions, forecasting and offers a better understanding of where prospective patients are in the system, including any geographic and demographic variances.
- Being able to access data helps a manufacturer to understand treatment outcomes and address areas of uncertainty. For instance, access to longitudinal data on secondary breast cancer would allow for the comparison of a therapeutic intervention in a modern patient cohort against historic data for similar populations.
- The translation of randomized controlled trial (RCT) data to real-world clinical settings can be challenging, particularly for more targeted therapies, of which there are many emerging in the cancer therapy area.
- From a health technology appraisal perspective, access to high quality data will help to address many of the clinical and economic uncertainties that arise in appraisals, and thus improve access to innovative treatment which improve patient outcomes. It can help when assessing the cost-effectiveness of new therapies vs current benchmarks.
- Linked genetic/genomic/pathology and imaging data would really add tremendous value to such a data set. It would be part of an incredibly important ecosystem making the UK a very attractive place to conduct all sorts of health-related research. All of this could help improve commercial decision-making when it comes to bringing pipeline products to come to fruition and help to facilitate greater investment in the UK from multinational companies.
- Delivering a new audit in breast cancer would be a long-term project requiring resource in every hospital in the UK. Other therapy areas have experience of delivering and operationalising clinical audits of this scale, including in the areas of prostate and lung cancer. Adopting the key learnings from these audits on overcoming barriers to implementation would be recommended.

3. Conclusion and next steps

Emma Lavelle

- Raised Breast Cancer Now and legacy organisation Breast Cancer Care championing the importance of data collection for several years, from working in partnership on the NCIN's pilot project in 2012 through to the more recent Unsurvivors campaign.
- Said that we know that those living with secondary breast cancer experience delays in diagnosis, struggle to access the support of a specialist nurse and fear they will not be able to access the treatment they need in the future.
- Said data is the key to making progress in these areas and that Breast Cancer Now was really pleased to hear that this is something the Minister and the APPGBC will be working on.
- Started summarising the key areas covered by saying that, across the clinical community and industry, it was clear that there was a desire for consistent and complete data.
- Highlighted Claire's speech and said that patients want to see this happen and are frustrated by the slow progress. There is no time to waste on this.
- Wide ranging benefits of a Secondary Breast Cancer Audit mentioned:
 - Assessment of compliance with national/international guidance.

- Enabling us to see what treatments patients receive and when, therefore understanding better the effectiveness of treatments, and of different treatment pathways.
- Help with clinical trial design.
- Encourage research to come to the UK.
- Understanding the number of people who could benefit from a new treatment – useful for planning purposes.
- Enabling commissioners and healthcare providers to understand their local patient populations.
- Enable the case to be made for more resources for Secondary Breast Cancer patients.
- Enabling increased capacity to deal with new treatments coming down the line and increased demand (E.g., increasing use of CDK 4/6 inhibitors).
- Potential to improve access to treatments – high quality data would assist in cost-effectiveness analysis in HTAs.
- Priorities for an audit included:
 - Clinical nurse specialists.
 - Treatment outcomes.
 - Clinical trials.
 - Palliative care services.

Craig Tracey MP

- Thanked all speakers and attendees.
- Said all the information will be compiled and sent to Department of Health and Social Care and NHS England. We will use all that you have presented in our continued efforts to improve data collection on secondary breast cancer.
- Concluded the meeting.