



APPG on Breast Cancer

TWO YEARS ON: AGE IS STILL JUST A NUMBER

Progress Report on the All Party Parliamentary Group on
Breast Cancer's inquiry into older age and breast cancer

This report has been produced in association with



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INTRODUCTION

In January 2013 the All Party Parliamentary Group on Breast Cancer (APPGBC) assembled a panel of nine MPs and peers, chaired by Steve Brine MP, to undertake an inquiry into the diagnosis and access to treatment, care and support for older people^a with breast cancer.

The statistics surrounding older people and breast cancer are stark:

- More than half of breast cancer deaths in the UK are in women over 70¹.
- By 2040, almost three-quarters of all women living with breast cancer in the UK will be aged over 65. The proportion of older women (aged 65 and older) living with breast cancer will increase from 59% today to 73% in 2040.
- Today there are around 340,000 older women living with a diagnosis of breast cancer in the UK. By 2040, this is projected to increase to 1.2 million – an almost four-fold increase².
- Older women are 46% more likely to be diagnosed with an advanced stage of breast cancer than younger women³.

Despite this, it appears that many older people may not be receiving the level and type of support, treatment and information they need. The APPGBC therefore set out to understand more about these variations and identify barriers preventing all patients diagnosed with breast cancer having access to the services, treatments and care that will benefit them most, regardless of their age. Focusing on three broad themes – breast cancer risk and

early diagnosis, access to gold standard treatments and access to information and support – the Inquiry made nine recommendations to ensure that older breast cancer patients receive the treatment and care that is most appropriate to them.

Whilst progress has been made, there is still a lot of work to do in ensuring that older people with breast cancer receive the care, treatment and support that is most appropriate to them and their circumstances. This update evaluates where progress has been made on the recommendations made by the Inquiry, identifies where there is still work to do and sets out, where appropriate, what action the APPGBC will take.

During 2014, the APPGBC held a series of roundtable sessions^b with a range of healthcare professionals and policy officials to discuss progress in each of the three areas. These three roundtables, along with research carried out by Breakthrough Breast Cancer on behalf of the APPGBC, informed the actions set out in this follow up report. As the roundtables were held under the Chatham House Rule, information in this report which was gained from the roundtables has not been attributed to individuals.

^a For the purposes of this inquiry, 'older people' were defined as those over 65.

^b In addition to members of the Inquiry Panel and representatives from Breakthrough Breast Cancer, Breast Cancer Campaign and Breast Cancer Care, the roundtables were attended by Sean Duffy (NHS England), Prof Julietta Patnick (Public Health England), Anna Garratt (Department of Health), Dr Claire Stephens (Barnet Clinical Commissioning Group), James Brandon (Public Health England), Neil Churchill (NHS England), Kwok-Leung Cheung (University of Nottingham), Kim Diprose (Macmillan Cancer Support), Richard McMahon (National Cancer Peer Review), Tim Elliott (Department of Health), Prof Sir Bruce Keogh (NHS England), Chris Carrigan (National Cancer Intelligence Network), Dr Alistair Ring (Royal Marsden) and Selina Mehra (Macmillan Cancer Support).

TACKLING LATE PRESENTATION

RECOMMENDATION 1

Invest in sustained breast awareness campaigns for older women.

The Department of Health's *Be Clear on Cancer* campaign includes a component focusing on breast cancer in women over 70 in recognition of the need for older women to be aware of their risk and the importance of targeting this age group. The Inquiry recognised the potential for this campaign to have a significant impact and made the following recommendations in this area:

- It is strongly recommended that as the overarching *Be Clear on Cancer* campaign develops, the specific focus on breast cancer in women over 70 should not be lost, given the clearly identified need for tailored breast cancer awareness messages for older women.
- Public Health England should support on-going evaluation and, if appropriate, national roll-out of the *Be Clear on Cancer* 'Breast Cancer in Women Over 70' campaign across England by 2014.

people sometimes worry about wasting a GP's time. *Be Clear on Cancer* featured real GPs inviting people to come and see them, something that older people in particular responded well to⁴.

Prior to national roll out, there were regional pilots of the *Be Clear on Cancer* 'Breast Cancer in Women Over 70' campaign. These showed that:

- 7% of women aged 40 and over at the pre-campaign stage correctly believed that women in their 70s are more likely to develop breast cancer than younger women, with a statistically significant rise to 25% post-campaign⁵.
- In the pilot areas, 43% of people recalled receiving *Be Clear on Cancer* material in the post, compared to 31% in the control areas⁵.

APPGBC response:

Public Health England is to be congratulated on rolling out the Women Over 70 campaign and the initial results are promising. The APPGBC will continue to monitor the success of the campaign and consider further action once a full evaluation has been made.

Progress since the Inquiry

A six week national roll-out of the *Be Clear on Cancer* 'Breast Cancer in Women Over 70' campaign started in February 2014. Whilst evaluation data for the national campaign is not yet available, initial results show that there is good awareness of the campaign among GPs. There was a concern that this campaign would result in GPs being inundated with the 'worried well' but this did not materialise and most people who have visited their GP as a result of the campaign have had genuine concerns⁴. It has been suggested that the *Be Clear on Cancer* campaign is likely to be successful among older people because older

RECOMMENDATION 2

Support targeted interventions for increasing breast awareness in older people.

The Promoting Early Presentation (PEP) Intervention was an evidence-based targeted intervention developed to increase breast awareness in older women. The PEP provides women with information on the importance of breast awareness, the signs and symptoms to look out for and also tackles the misconception that women over 70 are no longer at risk of developing breast cancer. It was developed by researchers at King's College London and is designed to be delivered by a radiographer during a woman's final routine invitation breast screening appointment. There are also a range of smaller, grass roots projects which are aimed at improving breast awareness throughout England. The Inquiry recognised the significance of these projects and made the following recommendations:

- Funding should be secured for Public Health England to support further roll out of the Promoting Early Presentation (PEP) Intervention and gain stronger evidence for its benefits for improving breast awareness and survival outcomes for breast cancer in older women.
- In addition to its use in NHS breast screening services, King's College London Early Cancer Presentation Group should be supported to test the PEP Intervention across a variety of community-based healthcare settings to maximise exposure to a range of population groups, and where possible a focus on ethnic minority and deprived groups in England, and women with additional needs.
- Other grass-roots interventions, including those targeting women who do not attend screening, should be evaluated and support given to those that are shown to deliver highest impact in raising breast awareness in older women.

Progress since the Inquiry

The King's College London PEP Group closed in 2014 and it appears that little progress has been made in this area⁶. This work did form part of the Department of Health's Policy Research Unit into Cancer Awareness, Screening and Early Diagnosis and it is possible that some strands of this work may have been picked up through that programme.

Grass-roots interventions are continuing in this area – between July 2013 and March 2014, 1,149 people over the age of 69 were reached through Breast Cancer Care's Train the Trainer Programme⁷. The report also highlighted the local projects piloted as part of the National Awareness and Early Diagnosis Initiative (NAEDI) as an example of a grass-roots intervention. However, at present it does not appear that any of the local NAEDI projects are specifically about breast cancer⁸.

APPGBC response:

It is disappointing that relatively little progress has been made in this area. The PEP Intervention was a promising breast awareness programme for older women and the APPGBC is concerned that this activity appears to have ended. The lack of breast cancer specific activities in the NAEDI programme is also a cause for concern. The APPGBC will follow this up with the key people involved in these programmes to ask about future plans. Further support should be given to initiatives such as the Train the Trainer Programme.

RECOMMENDATION 3

Gather evidence for the benefits and risks of breast screening for women above the current screening age.

Breast screening plays an important role in the early identification and diagnosis of breast cancer. In England, women between 50 and 70 years of age are routinely invited every three years for breast screening by the NHS Breast Screening Programme, but whilst breast screening is still available to women over 70, they are required to make their own appointments. The Inquiry Panel were convinced that further investigation of the risks and benefits of breast screening in women over 70 is vital for improved decision making and future targeting of the NHS Breast Screening Programme and made the following recommendations:

- Funding should be secured from NHS England for Public Health England to support an additional round of invitational breast screening as part of the NHS breast screening age-extension trial. This would extend invitations to study participants aged 74-76 years of age for an additional round of screening. It is important that this is implemented quickly to ensure that those who have participated in previous rounds of the study can continue to be involved in the trial.
- Providing there is sufficient take-up in the 74-76 age range, the age extension trial should be further extended to invite participants between 77 and 79 years of age.

Progress since the Inquiry

Public Health England remains very supportive of a potential continuation of the age extension to 76 in the first instance. In addition, the age extension trial has been well received by healthcare professionals in areas that are participating and is well supported by local practices and practice staff. However, issues have been identified around funding. At present two thirds of the funding is being spent on women at the younger end of the age extension trial (ie, 47-49) as there are more younger women. This means that there is limited funding available for the age extension into the older group and there appears to be little possibility of securing additional funding⁴.

APPGBC response:

Whilst we recognise the budgetary pressures existent within the NHS, the Group is disappointed that our recommendation to extend the age extension trial to women aged 74-76 has not yet been taken forward. The Cancer Taskforce set up by NHS England to assist in the development of a new Cancer Strategy should review this issue and endeavour to find a way to take forward this recommendation.

ACCESS TO GOLD STANDARD TREATMENT

RECOMMENDATION 4

Develop a practical evidence-based tool to measure patients' fitness for treatment to help inform decisions and ensure effective management of comorbidities.

The Inquiry heard that many patients do not have all of their needs assessed adequately and therefore their care is often not coordinated as it should be. The Inquiry made the following recommendations in this area:

- NHS England should identify or develop a suitable frailty assessment for people with cancer and monitor implementation of this as part of the Cancer Peer Review Programme.
- The professional organisations representing oncologists and geriatricians, including the Royal Colleges of Radiologists, Surgeons and Physicians and the British Geriatric Society, should establish a model of joint working between these specialties to ensure that decisions regarding the treatment and care of older people are appropriate and as informed as possible.

Progress since the Inquiry

Starting in 2012, the International Society of Geriatric Oncology (SIOG) carried out extensive work in this area but has not identified one screening tool that should be used above all others. However, SIOG does recommend that functional status, comorbidity, cognition, mental health status, fatigue, social status and support, nutrition and presence of geriatric syndromes are evaluated when assessing older cancer patients. SIOG has also assessed 17 screening tools that could be used in busy clinics where full geriatric assessment might not be possible⁹. It has also been highlighted that any tool used would need to be valid so that if somebody

'fails' the screening tool and treatment is subsequently withheld, this must be justified. There must also be services available to help support a patient who 'fails'. It has also been suggested that a service specification rather than the National Cancer Peer Review might be the best way to monitor the implementation of a frailty assessment⁴.

In 2014 the Liverpool Reviews and Implementation Group published a systematic review exploring the effectiveness and tolerability of chemotherapy in older people with breast cancer. This review found that:

“ Studies generally conclude that chemotherapy is a feasible treatment option for older people with breast cancer. The data suggest that older people can tolerate chemotherapy, although treatment comes with a risk of more serious AEs^c. In comparison to younger patients, the results were broadly similar, which suggests that age should not be a barrier to treatment for breast cancer, and that older age should not disqualify people from being eligible for clinical trials. ”¹⁰

The Association for Cancer Physicians held a study day focusing on cancer care in elderly patients in October 2014. One of the outputs of this event was to be a handbook for physicians about care of older cancer patients¹¹.

APPGBC response:

The APPGBC is encouraged that significant effort is being put into the development and identification of frailty tools to be used in clinics and that care for older people with cancer is seen as a priority for professional groups. NHS England must now look to encourage clinicians to adopt available tools to help with decision-making. The APPGBC will be monitoring progress in this area, particularly around implementation of a frailty tool in the NHS.

RECOMMENDATION 5

Support better use of data to establish the most appropriate treatment for older people with breast cancer.

The Inquiry heard how many of the problems associated with the treatment and care of older people with breast cancer are underpinned by a lack of data in this area and made the following recommendations:

- Public Health England should ensure that data on the diagnosis and treatment of older women with breast cancer, including information on comorbidities and frailty, is collected and analysed.
- Public Health England should ask the NCIN to conduct an analysis of the diagnosis and treatment of older women with breast cancer to identify differences in experiences both nationally, compared to other age groups, and regionally to identify differences in performance at the local level. This information should be reported to Ministers, NHS England and CCGs.

However, due to the controversy around data protection caused by the introduction of care.data as well as changes to the structure and resource of the NCIN, this data has not been as readily available over the last year as it has in the past. In addition, issues around resourcing and prioritisation mean that funding for this activity is not as forthcoming as it has been previously⁴.

Age is Just a Number has contributed to a wider discussion about older people and breast cancer and in January 2015, the Healthcare Quality Improvement Partnership consulted on introducing a breast cancer audit focusing on breast cancer care in the older patient. Suggested audit measures include MDT discussion, access to a breast care nurse, treatments offered and reasons for patients not being offered or declining treatments^d.

APPGBC response:

The Group sees great value in the proposed audit by the Healthcare Quality Improvement Partnership and awaits the results of the consultation with interest.

Progress since the Inquiry

There is no question among healthcare professionals that data is essential to ensure that people are receiving the most appropriate treatment for them. During the roundtable session discussing use of data, it was explained that by using data from Hospital Episode Statistics (HES) and the Cancer Outcomes Services Dataset (COSD), the National Cancer Intelligence Network (NCIN) is able to create a list of treatments and side effects that a person has experienced throughout the patient pathway and this then results in a comorbidity score. The lack of older patients on clinical trials means that there is a gap in the available data. These datasets play an important role in addressing this gap.

^d Full audit measures and further information about the audit can be found at <http://www.hqip.org.uk/breast-cancer-audit>

RECOMMENDATION 6

Ensure that the requirements of older people are fully taken into account when developing and updating breast cancer guidelines.

The Inquiry noted the lack of specific guidelines relating to older people and breast cancer and made the following recommendations:

- The National Institute for Health and Care Excellence (NICE) and the Association of Breast Surgery (ABS) should involve geriatricians when updating breast cancer guidelines to ensure that the needs and views of older breast cancer patients are taken into account.
- NHS England should clarify how performance against the Breast Cancer Quality Standard, and in particular the statement which applies to older people, will be monitored at a national level.
- All bodies responsible for developing future guidelines that impact on breast cancer patients should ensure that the needs and views of older patients are taken into account.

Progress since the Inquiry

Clinical Commissioning Groups (CCGs) are legally obliged to take due regard of all quality standards and the intention is to refresh them so that what was once considered best practice becomes the norm. It is the role of NHS England to hold CCGs to account, however it has been acknowledged that NHS England has not yet established protocols for this⁴.

The breast cancer measures used by the National Cancer Peer Review programme to assess breast multi-disciplinary teams included criteria on several key statements of the Breast Cancer Quality Standard, and therefore could be used to evaluate levels of compliance with the standard across the country. However, the National Cancer Peer Review programme is currently under review, and it is thought that any new programme that replaces it is likely to focus on clinical outcomes more than process measures.

APPGBC response:

The APPGBC is concerned about the future of the Cancer Peer Review Programme and has written to NHS England to seek assurances that Peer Review and/or any future quality assurance programme that is introduced in replacement of it continues to include measures on key process-related statements of the Breast Cancer Quality Standard.

ACCESS TO INFORMATION AND SUPPORT

RECOMMENDATION 7

All older breast cancer patients are provided with the information they need about their treatment, in the way that they wish to receive it.

The Inquiry heard about the importance of appropriate information for older patients and made the following recommendations:

- Healthcare professionals discussing a diagnosis of breast cancer with a patient need to ask about the patient's information needs to ensure that high-quality information is provided appropriately. This must be followed up throughout the patient's treatment.
- Breast units should make available a range of high-quality information about all aspects of cancer treatment and support services. This needs to be available in a range of formats including online, hard copy written material, large print and different languages. Breast units should also provide information on helplines, support groups and peer support services for patients who would appreciate this type of information. Commissioners should require all breast units to conduct audits of the information provided to patients.

Progress since the Inquiry

Access to a clinical nurse specialist (CNS) is essential to the provision of information about cancer treatment as well as access to non-treatment related information. The National Cancer Patient Experience Survey shows a clear correlation between access to a CNS and having adequate non-treatment information (finances, benefits, etc)¹². It has also been suggested that the increase of publically available data on the performance of local services could be a lever for improvement, as Trusts know that the public can access this information and this provides an incentive to improve⁴.

NHS England have worked with Carers UK to develop commitments around ensuring that carers and family members have access to the information they need. There are plans to explore this area more with other carers' organisations⁴. NHS England are also developing an Information Standard for accessible information aimed at improving the availability of accessible information for patients with disabilities⁴.

APPGBC response:

The Group is pleased to see the focus that has been placed on providing information for families and carers and will continue to monitor the availability of appropriate information for older breast cancer patients.

RECOMMENDATION 8**Ensure all breast cancer patients have their needs fully assessed.**

The Inquiry heard how there is confusion about how breast cancer patients should have their needs assessed and made the following recommendations:

- NHS England should commission a review of available needs assessment tools to identify the most practical and cost-effective tool for use in a breast clinic setting.
- NHS England should incentivise (for example through Cancer Peer Review and CQUIN) the use of a needs assessment tool for all breast cancer patients.

Progress since the Inquiry

As detailed above, the International Society of Geriatric Oncologists (SIOG) has carried out extensive research in the area of needs assessments for older cancer patients. However, this research has not resulted in one assessment tool being recommended above others. It has highlighted that any assessment tool that is used should assess functional status, comorbidity, cognition, mental health status, fatigue, social status and support, nutrition and presence of geriatric syndromes¹⁰.

APPGBC response:

The Group applauds SIOG's focus on the use of needs assessment tools for older cancer patients and will continue to monitor how these tools are used within the NHS.

RECOMMENDATION 9

Ensure all necessary support services, including psychosocial support, for breast cancer patients are in place to allow cancer treatment to begin within cancer waiting time targets.

The Inquiry heard that many older patients did not have the necessary support services in place to allow cancer treatment to begin and made the following recommendation:

- Local agreements should be in place to ensure that all breast cancer patients have timely access to the support services they need. These should be led by Clinical Commissioning Groups in collaboration with local authorities and other relevant stakeholders. These are crucial to ensure that older patients in particular are not missing out on or having to delay their cancer treatment.

Alongside this, clinicians should look to 'socially prescribe' services run by voluntary sector organisations to patients to provide support that health and social care services are not able to provide. Breast Cancer Care's Moving Forward course can help individuals following treatment cope and manage with moving past breast cancer diagnosis and treatment, as well as encouraging people to spot the signs and symptoms of a possible recurrence.

APPGBC response:

It is disappointing to see lack of progress in this area and uncertainty around the future of the Cancer Peer Review Programme. Whilst the APPGBC appreciates that the issue of integrating health and social care is much wider than breast cancer, this is an issue that requires urgent attention across government and the NHS. The Group will continue to monitor the integration of health and social care services and the impact that this has on care for older people with breast cancer.

Progress since the Inquiry

The integration of health and social care is a difficult issue and one that successive Governments and the NHS have struggled to tackle. It is clear that more needs to be done to integrate health and social care services to ensure that cancer patients have access to the support services that they need in order for their cancer treatment to take place.

The National Cancer Peer Review Programme breast measures include an expectation that all patients should be offered a key worker and assessment of their physical, emotional, practical, psychological and spiritual needs¹³. However, the roundtable discussion of this recommendation concluded that many units struggle to meet this standard, particularly to continuously assess patients throughout their treatment as well as at diagnosis⁴. Macmillan Cancer Support has established a geriatric expert group to look at issues such as these⁴.

CONCLUSION

In the two years since the APPGBC Inquiry it is encouraging to see that some progress has been made to improve services for older breast cancer patients. However, we are concerned at the slow pace of change and the limited progress made in implementing these recommendations in key areas.

There is still a long way to go to improve treatment and care for older breast cancer patients. The APPGBC will be playing an active role in following up these recommendations to ensure that all older breast cancer patients receive the treatment that is most appropriate to them throughout the next parliament.

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Breakthrough Breast Cancer provides the Secretariat to the All Party Parliamentary Group on Breast Cancer

The All Party Parliamentary Group on Breast Cancer: offers the opportunity to hear from people directly affected by breast cancer provides advice and information about national and constituency issues relating to breast cancer supports members to participate in Parliamentary meeting, debates and questions on breast cancer issues

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