

Evidence from Breakthrough Breast Cancer – CDP 26

1. Breakthrough Breast Cancer welcomes the opportunity to submit evidence to the National Assembly for Wales' Health and Social Care Committee's inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan. Breakthrough Breast Cancer is dedicated to improving and saving lives through breast cancer prevention, early diagnosis, more targeted treatments and better services for everyone affected by breast cancer.
2. We note that section 2.1 of the *Together for Health* annual report mentions the importance of new and effective treatments and the impact these treatments have on improving outcomes. Breakthrough Breast Cancer agrees and in the last year we have seen three very promising breast cancer drugs introduced to the UK market. These are drugs for secondary or metastatic breast cancer – this is breast cancer that has spread outside of the breast to another part of the body. Unfortunately, at this stage, breast cancer cannot be cured but it can be controlled for months and sometimes years. These new treatments offer women with secondary breast cancer extra, good quality time to spend with their friends and family. Unfortunately these treatments are extremely expensive and the National Institute for Health and Care Excellence (NICE) has rejected two of them and is currently considering the third. NICE guidance applies to Wales in this case because these drugs meet the All Wales Medicines Strategy Group's exclusion criteria. We are encouraging NICE and the Government to work with the pharmaceutical industry to establish a system where these drugs can be made routinely available to patients in the long term, at a price that is sustainable for the NHS but still acceptable to industry.
3. In England there is a temporary solution to the problem of access to these drugs as they are available through the Cancer Drugs Fund. While the Cancer Drugs Fund is not a permanent solution to the problem of access to medicines, it is benefitting patients who need these drugs now. However, there is no Cancer Drugs Fund in Wales and the NHS in Wales follows NICE's guidance, meaning that cancer patients in Wales are missing out on the treatments they need. We know that patients in Wales can request access to medicines through Individual Patient Funding Requests but we have heard anecdotally that patients struggle to access the treatments they need through this system. We would suggest that this system is reviewed to ensure that patients are able to access the treatments they need and it is as transparent and easy to use as possible. This will ensure that cancer patients in Wales have access to the treatments that patients in England are able to access through the Cancer Drugs Fund.
4. Sections 4.0 and 5.0 of the *Together for Health* annual report focus on the prevention and early detection of cancer. Prevention and early detection are priority areas for Breakthrough

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Breast Cancer and we are pleased to see that the Welsh Government's Cancer Delivery Plan places so much emphasis on these areas. However, we note that there is no mention of prevention or early detection specifically for people who have a higher risk of developing cancer because of their family history. In a small number of cases, breast cancer runs in the family – around one in five breast cancers are thought to be caused by a family history of the disease.

5. Last year NICE issued comprehensive new guidelines on the care and treatment of people with a family history of breast cancer. Amongst other recommendations, these guidelines have lowered the threshold for genetic testing for faults in the breast cancer genes meaning that more people are now eligible for genetic testing, extended the recommendations for enhanced surveillance for women at higher risk and introduced chemoprevention drugs such as tamoxifen and raloxifene for women at a higher risk of breast cancer because of their family history. These guidelines will help women to understand their risk of breast cancer and gives them options to help them manage their risk.
6. Breakthrough Breast Cancer believes that it is essential that these guidelines are implemented in both England and Wales. We have heard anecdotally that there are problems in Wales with both access to genetic testing and access to MRI screening for people at a higher risk of developing breast cancer due to their family history. We would therefore be interested to know what is being done to address these problems and to ensure that services are in place so that people with a family history of breast cancer are able to access the services they need. We also know that throughout England and Wales, there is uncertainty around the provision of chemoprevention drugs as these drugs have not previously been available for this purpose in the UK. We would therefore be interested to know about the Welsh Government's plans for ensuring that eligible women have access to these drugs.
7. We are pleased to see the focus on improving waiting times in section 7.2. We know that the earlier breast cancer is found and diagnosed, the better chance there is of successful treatment. We have been concerned for some time about the length of time Welsh women who are referred to a breast clinic by their GP have to wait for an appointment with a specialist, particularly women who are referred through the non-urgent pathway. We have been in contact with Health Boards across Wales about average waiting times for women referred to a breast clinic and have been concerned to learn that the length of time women wait for an appointment is not routinely monitored and for those Boards that do monitor this, some have waiting times of up to 28 weeks for an appointment. We know from speaking to women that the time spent waiting for an appointment at a breast clinic is an

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incredibly anxious one. It is important that these women are seen by a specialist as soon as possible. If they are diagnosed with cancer, this will ensure that treatment can begin as early as possible. For women who are referred to a breast clinic but do not receive a diagnosis of breast cancer, a quick appointment means they are spared a long period of anxiety, worrying that they may have cancer.

8. We have been in contact with the Health Minister about this and we know that plans are in place to reform cancer waiting times in Wales. We are hopeful that these plans will ensure that women referred to breast clinics are seen by a specialist as early as possible. Breakthrough Breast Cancer will continue to work with the Welsh Government to ensure that waiting times for women referred to a breast clinic by their GP are kept to a minimum.
9. Breakthrough Breast Cancer was encouraged to see the emphasis on meeting people's needs (section 13.0) and the results from the 2013 cancer patient experience survey. We note that breast cancer patients overall tended to be more positive about their care than other cancer patients which shows that breast cancer services are performing well. However, there is always room for improvement and we hope that results from the survey are fed back to individual hospitals to help them to identify areas where changes are needed to enhance the service. Through our 'Service Pledge for Breast Cancer' Breakthrough Breast Cancer works with patients and hospital staff to identify what works well in a specific service and what could be changed. We then work with hospitals to identify improvement goals to ensure that patient experience is continuously advancing. We would be happy to discuss the possibility of working with hospitals where breast services are not performing as well as they could be. We would also be happy to discuss the possibility of adapting the Service Pledge for other cancers as well as breast cancer. For further information about the Service Pledge, please see www.breakthrough.org.uk/servicepledge.
10. There is no information in the *Together for Health* annual report about the future of the cancer patient experience survey. It is important that the cancer patient experience survey is repeated and reported on a regular basis, preferably annually. This would ensure that the experiences of cancer patients continue to improve because hospitals can identify local issues that need addressing and the Welsh Government would be able to identify patterns of issues that needed to be addressed on a national level.
11. Thank you for the opportunity to submit evidence to the National Assembly for Wales' Health and Social Care Committee's inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan.