National Assembly for Wales
Health and Social Care Committee

Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan

Evidence from ABPI Cymru Wales- CDP 21

ABPI Cymru Wales Submission to the Health & Social Care Committee inquiry on implementation of the Welsh Government Cancer Delivery Plan

April 2014

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Who We Are:

Association of the British Pharmaceutical Industry

The Association of the British Pharmaceutical Industry (ABPI) represents innovative research-based biopharmaceutical companies, large, medium and small, leading an exciting new era of biosciences in the UK.

Our industry, a major contributor to the economy of the UK, brings life-saving and life-enhancing medicines to patients. Our members supply 90 per cent of all medicines used by the NHS, and are researching and developing over two-thirds of the current medicines pipeline, ensuring that the UK remains at the forefront of helping patients prevent and overcome diseases.

The ABPI is recognised by government as the industry body negotiating on behalf of the branded pharmaceutical industry for statutory consultation requirements including the pricing scheme for medicines in the UK.

Contact Us:

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Background
The Association of the British Pharmaceutical Industry (ABPI) Cymru Wales welcomes the opportunity to provide evidence to the National Assembly for Wales Health and Social Care Committee *"Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan".* We have used the progress outlined in the The *Together for Health Cancer Delivery Plan Annual Report 2013*[1] to support this submission. This important document highlights the progress made over the previous 12 months against the ambition of measuring successes in the treatment of cancer against the best countries in Europe, as well as identifying areas for future improvement.

ABPI Cymru Wales has based this submission on the terms of reference and key areas of progress outlined in the Committee's invitation to contribute to their Inquiry. We hope this is helpful and understand that submissions to the Inquiry may be made public – on the internet or in a report. We are happy for the comments made to be attributed to ABPI Cymru Wales.

Please note that as a trade association, the ABPI do not comment on specific treatments, which are more appropriately the province of our members who have expertise in individual therapy areas.

[1] http://wales.gov.uk/docs/dhss/publications/140320cancer-planen.pdf

Rather, we have provided a general commentary on the implementation of the Delivery Plan and the potential priorities, which the Committee may wish to consider. Specifically, we have continued to raise concerns at the lack of reference to medicines within the implementation of the Cancer Delivery Plan. We would argue that medicines are an essential element of care, which do not receive adequate attention in the Plan. The Health and Social Care Committee may, in particular, wish to consider the issues relating to patient access to cancer medicines during this Inquiry.

Summary

- Appropriate measures should be included throughout the Plan, to ensure transparent reporting of progress can be monitored
- Whilst Wales' cancer survival improvement has been proportionately larger - in some disease sites, we often still lag behind the rest of the UK and other European countries
- The development of new and more effective treatments mean that many more people can now expect to live longer due to their cancer treatment
- There are issues relating to the availability of, and access to, medicines for patients with cancer across Wales, due to the limitations of Health Technology Assessment (HTA) methodologies used by both All Wales Medicines Strategy Group (AWMSG) and National Institute for Health and Care Excellence (NICE) and the continued absence of alternative funding routes
- Current Individual patient Funding Request (IPFR) processes often do not provide a suitable alternative source of funding for cancer medicines not approved by AWMSG or NICE due to restrictive exceptionality criteria
- There is evidence suggesting that some of the latest cancer medicines are less available in Wales than elsewhere in the UK
- The implementation of the Cancer Delivery Plan should prioritise the transparent monitoring and reporting of the availability and uptake of cancer medicines
- Stratified medicines are formulated to target disease in patients with specific genetic profiles. These new medicines and innovative technologies will require new diagnostic systems and molecular tests. The managed entry and availability of appropriate diagnostic tests is not addressed in the Cancer Delivery Plan
- It is disappointing if Wales misses out on clinical trials placement and investment because new 'gold standard' trial comparator medicines are not already in routine use
- The pharmaceutical industry has agreed to keep expenditure on branded medicines flat for two years followed by 3 years limited increases as agreed between the ABPI and the Department of Health. During this time, the pharmaceutical industry will underwrite any extra expenditure in the use of branded medicines by the NHS that exceeds the agreed boundaries

1. Whether Wales is on course to achieve the outcomes and performance measures as set out in the Cancer Delivery Plan by 2016?

1.1 ABPI Cymru Wales has previously welcomed the Welsh Government's commitment to match the best outcomes in Europe for those with cancer. The *Together for Health Cancer Delivery Plan Annual Report 2013*[2] notes that *"Good progress is being made in implementing the actions set out in the Cancer Delivery Plan"* and it is welcome that *"Wales has shown the biggest improvement in cancer survival among the four countries of the United Kingdom".* It is also noted that *"There are however some areas where progress has not been as good as anticipated"* and that *"Whilst Wales's cancer survival improvement has been proportionately larger than in other UK countries, we are lagging behind a number of other European countries"*.

1.2 Reference is made to Eurocare 5[3], which compares cancer survival across different countries in Europe. The Committee may wish to consider the following extracts:

"The low survival of UK and Danish cancer patients has been extensively analysed; the main cause seems to be delayed diagnosis. Underuse of potentially successful treatments (possibly related to advanced stage at presentation) and poor or unequal access to treatment also seem to play a part".

"The increases in survival over time and disparities in cancer survival across Europe suggests that further improvements could be made by application of proven treatment protocols and ensuring that all cancer patients have access to early diagnosis and high quality treatment."

According to Eurocare 5, despite Wales showing UK best survival for kidney cancer, Wales was also lagging behind the rest of the UK for colon, rectal, lung, skin, breast and prostate cancers.

1.3 For the Welsh Government to achieve its ambition to match the best outcomes in Europe for those with cancer, the implementation of the Cancer Delivery Plan should focus on all of the key factors mentioned above, in particular early diagnosis and patient access to the most effective treatments, including medicines. We assert that the commissioning and use of medicines are essential to effective management of any care pathway, including those in oncology. The Annual Report recognises that *"New and more effective treatments mean that many more people can now expect to live longer after their cancer treatment"*. The Committee may wish to query why the uptake and availability of new and more effective treatments is not included in the report.

2. Progress made in reducing the inequalities gap in cancer incidence and mortality rates

2.1 The report notes that *"Although survival rates are improving, the rates are still quite variable amongst commonly occurring cancers"* and *"Much more needs to be done to improve survival."* Ensuring that patients are able to access new and more effective treatments may help support the progress to improve the inequalities gap in cancer incidence and mortality rates.

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[2] http://wales.gov.uk/docs/dhss/publications/140320cancer-planen.pdf

[3] Cancer survival in Europe 1999—2007 by country and age: results of EUROCARE-5—a population-based study. The Lancet Oncology, Volume 15, Issue 1, Pages 23 - 34, January 2014

2.2 In 2013, analysis from the Office of Health Economics (OHE)[4] confirmed that the UK lags behind comparable countries in terms of use of branded medicines. This followed on from The International Variations in Drug Usage Report[5] which, worryingly, showed that for patients suffering from a range of conditions, including cancer, the UK had fallen behind most countries with similar economies and health systems.

2.3 The work of the International Cancer Benchmarking Partnership[6] has shown the contribution to improving survival rates that high quality treatment for patients with advanced forms of lung, breast and ovarian cancer can make. Many of the cancers with the highest survival rates are also those characterised by significant improvements in treatment on recent years. News that prostate cancer mortality rates have declined by 20% over the past two decades shows what can be achieved. But for every breast cancer, prostate cancer or lymphoma, there is a lung, pancreatic or oesophageal cancer, where outcomes remain stubbornly poor.

2.4 A recent report from the University of Bristol[7] highlighted that *"Patients suffering from cancer in England are up to seven times more likely to be prescribed expensive cancer drugs than fellow sufferers in Wales"*[8]. The research by the University of Bristol also noted the rapid introduction of some NICE approved medicines in Wales, which is to be welcomed. However, the overall picture is not clear and given conflicting reporting on this issue, we would suggest that the Committee investigate further the comparative availability and uptake of cancer medicines in Wales. AWMSG and Welsh Analytical Prescribing Unit (WAPSU) will be able to provide further and specific evidence in this area to the Committee.

2.5 We would suggest that the Committee investigate the impact of any inequity in access to cancer medicines comparing Wales to the rest of the UK and Europe.

3. The effectiveness of cancer screening services and the level of take up across the population of Wales, particularly the harder to reach groups.

3.1 Early diagnosis is a vital factor in improving outcomes for patients with cancer, as is access to the latest proven treatments throughout the care pathway. The Annual Report recognises that *"More still needs to be done to ensure that those eligible are screened"*. ABPI Cymru Wales welcomes and supports the initiatives by Public Health Wales to raise awareness of national screening programmes. However, the work is not complete and early diagnosis should be a continuing priority for the implementation of the Cancer Delivery Plan.

4. Whether patients across Wales can access the care required (for example access to diagnostic testing or out of hours care) in an appropriate setting and in a timely manner.

4.1 The *Together for Health Cancer Delivery Plan*[9] made a number of commitments, including to

[4] OHE analysis for the ABPI, Benchmarking the uptake of new medicines in the UK – international perspective, 2013
[5] https://www.gov.uk/government/publications/extent-and-causes-of-international-variations-in-drug-usage
[6] http://www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/
[7] http://www.nature.com/bjc/journal/vaop/ncurrent/full/bjc201486a.html
[8] University of Bristol Press Release 4th March 2014: http://www.bristol.ac.uk/news/2014/march/cancer-drugs-fund.html
[9] http://wales.gov.uk/docs/dhss/publications/120613cancerplanen.pdf

- Find and treat cancer quickly and effectively using latest effective drugs and technology
- Speed up the introduction of known effective new treatments and technologies

To ensure these aspirations are met, we would suggest that routine and published monitoring of uptake and availability of cancer medicines should be prioritised within the measurement and reporting of progress.

4.2 ABPI Cymru Wales would also highlight to the Committee the changing nature of cancer treatments and new developments, which could fundamentally impact the way care is delivered. Increasingly, treatments - more commonly known as "stratified medicines" - are formulated to target disease in patients with specific genetic profiles. These new medicines require new diagnostic systems and molecular testing to allow therapies to reach those who would most benefit from them. The Committee will recall receiving evidence from ABPI during its inquiry into access to medical technologies. The managed entry and availability of appropriate diagnostic tests is not addressed in the Cancer Delivery Plan and may be another area that should be considered for inclusion in the on-going implementation measures to ensure that appropriate patients are being tested.

4.3 In Wales, AWMSG appraises all new medicines for which no NICE guidance is expected for at least 12 months from the date of submission (i.e. normally 6 months from AWMSG appraisal and the anticipated date of NICE final advice). This comprehensive and compulsory use of HTA introduces significant challenges for clinicians, patients and the pharmaceutical industry, especially;

- when the evidence-base needed for HTA appraisal may be limited e.g. treatments for ultra-orphan, orphan diseases and small applicable populations in Wales, and
- if the HTA methodology does not adequately capture and/or value the benefits of treatments for the disease area in question, such as cancer treatments or end of life / palliative care

We would suggest that significant HTA reform or alternative thinking is required to address gaps in the funding of innovative treatments. This is particularly the case for treatments which benefit defined patient cohorts and those suffering from rarer cancers.

4.4 Until very recently, in Wales, the only alternative route to funding a medicine not approved by AWMSG or NICE was for clinicians to progress their patients through an IPFR. These IPFR's are deemed time consuming and bureaucratic by patients and clinicians alike, and require evidence of patient "exceptionality" which excludes some individual patients and disqualifies multiple applications. The suitability and applicability of such a process for patients with cancer is doubtful. Concerns relating to the IPFR process have led the Minister for Health and Social Services to ask for a Review to be undertaken, which is due to report back to him by the end of March, 2014.

4.5 Whilst this Review of the IPFR process is on-going, AWMSG has agreed that if a new medicine – regardless of the disease area, but including cancer – is not recommended for use by NICE on the grounds of cost-effectiveness, an opportunity should be extended to the pharmaceutical company concerned to engage subsequently for further HTA re-assessment by AWMSG, who will be able to consider the evidence base in relation to the specific Wales context. However, it remains unclear and untested as to whether this additional re-assessment will overcome the current limitations with the HTA process and improve the range of medicines routinely funded.

4.6 The Welsh Government response to the Review of the Appraisal of Orphan and Ultra-Orphan Medicines in Wales, commissioned by the Minister for Health and Social Services in May 2013 is awaited and may also have implications for some patients with cancer. ABPI Cymru Wales would re-iterate our belief that this Review, alongside other areas of development in the appraisal of and access to medicines in Wales, needs to explicitly recognise the importance of appropriate and timely access to innovative medicines to maximise patient benefits from the NHS Wales budget.

4.7 In the meantime, the Governments in Scotland and England have introduced policy to improve access to innovative medicines. The approach in Scotland has been holistic and wide-ranging, with greater patient and clinician input, based upon a cross-party consensus driven by the recommendations of the Health & Sport Committee of the Scottish Parliament. These recommendations have been accepted and are being implemented by the Scottish Government Cabinet Secretary for Health and Wellbeing, who stated *"We have listened to the concerns raised by the Committee and we have taken decisive action in a number of key areas, which will increase access to new medicines within the NHS for patients in Scotland"*. This has included greater involvement of patients and clinicians in the medicines approval process. The Committee may wish to discuss, with their counterparts in Scotland, the work they have undertaken in this area and its implications in the treatment of cancer patients.

4.8 The Annual Report highlighted that *"… the development of an effective acute oncology service, the development of well defined pathways and an early assessment by a specialist oncologist should reduce extensive and often unhelpful investigations and ensure that the patient is placed on the appropriate pathway thus reducing the length of stay as a medical emergency. The cancer delivery plan has an expectation that all district general hospitals within Wales will have an acute oncology service by 2016 to better support this group of patients".* Whilst we appreciate that progress is being made to respond to this recommendation, there is anecdotal evidence to suggest that implementation is slow and inconsistent, which includes the ability for patients to access or remain on innovative treatments.

5. The level of collaborative working across sectors especially between the NHS and third sector to ensure patients receive effective person centred care from multi-disciplinary teams

5.1 The Annual Report states that *"The overall scores given by patients in Wales to the cancer patient experience survey were positive"*. Although this is to be welcomed, there remain areas for improvement. For example, there was a significant variation, dependent on tumour sites, in the proportion of patients saying they were given the name of a key worker. Also, only 58% of patients said they had been offered the opportunity to discuss their needs and concerns in order to put together their care plan. We would suggest the Committee seeks the views of patient organisations on the impact of this inequality and consider their views to develop improvements in this area.

5.2 ABPI Cymru Wales welcomes the 5% increase in the overall recruitment into clinical trials outlined in the Annual Report. We remain committed to working with the National Institute for Social Care and Health Research (NISCHR) and, where appropriate, Health Research Wales, to reach the target of all Wales recruitment of 7.5% into interventional studies. The pharmaceutical industry is the UK's biggest investor in health research, with investment totalling £4.4 billion per annum, which leads to the direct employment of 27,000 scientists and doctors, often working with colleagues in the NHS and universities.

5.2.1. At the end of last year, a survey by YouGov, which was commissioned by the Welsh NHS Confederation and supported by ABPI and the 1000 Lives Campaign, looked at the views of the Welsh public on their health services and treatments[10]. The Survey showed that an amazing 78% of respondents believed it was important that patients were encouraged to participate in research for the development of new therapies and medicines.

5.2.2. This is a staggeringly positive figure, and should act as encouragement for the Welsh Government, NHS Wales and researchers to ensure ongoing engagement with the public and patients in this area. This could provide the starting point for "Laboratory Wales", further enhancing the country's potential to become a fast-breeder for life sciences and the development of medicines.

5.2.3. However, there are implications and unintended consequences for countries which are not using "gold standard treatments" within their standard care pathways. ABPI Cymru Wales has anecdotal evidence of occasions where NHS Wales has been unable to accept the offer of investment in clinical trials from pharmaceutical companies because comparator "gold standard" medicines are not in use. The impact of losing out on such investment extends further than the obvious lost opportunity for patients. If decisions like these become more common it remains a worry that Wales will see a negative impact on its ability to attract and retain first class NHS staff and jeopardise external perception of Wales' research strength and expertise in cancer.

6. Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money

6.1 The report recognises the positive impact that new and more effective treatments have on improving outcomes and survival for patients with cancer. However, there is frequently a focus on the cost of medicines rather than an appreciation of the value that they can bring. As has been mentioned, ABPI Cymru Wales would suggest that inequity in the availability and uptake of innovative treatments needs to be investigated and addressed.

6.2 ABPI has delivered, with the UK Government, a new five-year pricing agreement to help ensure that patients across the UK, including Wales, get the medicines they need, when they need them, at no additional cost. Under this new arrangement, the pharmaceutical industry has agreed to keep expenditure on branded medicines flat for two years followed by three years of limited increases as agreed between the ABPI and the Department of Health for the UK as a whole. During this time, the pharmaceutical industry will underwrite any extra expenditure in the use of branded medicines by the NHS, within agreed boundaries. This means that the issue of affordability of newer innovative medicines has been taken off the table for the NHS. This should mean that doctors can exercise their clinical judgement without concerns for finance and be allowed to prescribe branded medicines more freely to patients who will benefit.

[10] http://www.nhsconfed.org/Documents/Survey%20Results%202014.pdf