



## All-Wales patient-held information folder

Established by the Wales Cancer Network, the All-Wales Systemic Anti-Cancer Treatment (SACT) Nurse Forum is chaired by Rosie Roberts, Chemotherapy Specialist Nurse from Velindre Cancer Centre.

**The Forum brings together senior nurses from across Wales who are working within the SACT arena to enable them to share best practice through collaboration and to inform the development of practice and workforce standards.**

Previous Forum work-streams have included the development of an All-Wales patient-held alert card for chemotherapy and immunotherapy, chemotherapy competencies and re-assessment.

Thanks to an education grant from ABPI Cymru Wales, the Forum has developed a standardised patient

information booklet for use by patients across Wales. The use of SACT has grown significantly over the past decade and the demand for treatment is expected to continue to rise by approximately 8% per annum.<sup>1</sup>

The South Wales Cancer Network's Guidance document for SACT Services (2015)<sup>2</sup> states the need to

ensure SACT patients receive information prior to the start of treatment. This development of standardised All-Wales information will replace the multiple versions currently used across Wales.

The aim was to create information that is:

- ▶ easy to read, using language that patients will understand
- ▶ small enough to be portable, for patients to bring with them to appointments
- ▶ free of endorsements of any specific products or brands
- ▶ suitable for local teams to adapt the content for local needs.

Main Image:  
*Members of the SACT Nurse Forum*

*Continued overleaf*

In order to achieve these goals, it was decided to create a folder of standardised information that would provide teams the opportunity to “pick ‘n’ mix” what is relevant to their patients’ needs. A working group created the content of the folder, drawing on existing information from Health Boards and Velindre Cancer Centre, as well as sources such as Macmillan Cancer Support and Cancer Research UK. The content includes key contact information, advice for other healthcare professionals such as GPs and dentists, a section on the common side effects that may occur because of their treatment, and a toxicity diary that allows patients to record any side effects they experience. The design means that the content of the folder can be adapted and updated as further information

becomes available, for example, a section related to immunotherapy will be developed.

Feedback from patient consultation showed 88% found the information useful or very useful, and 87% reported the print clear and easy to read. Following minor amendments from this engagement, the folders are now available bilingually and will be disseminated shortly. Thanks to the education grant from the ABPI, each Health Board and Velindre will receive a free initial batch of folders.

For more information on this All-Wales patient-held information folder, or the All-Wales SACT nurse forum, please contact Abigail. [Abigail.Hayward@Wales.nhs.uk](mailto:Abigail.Hayward@Wales.nhs.uk)

**My diary of side effects**

You may find it useful to keep a diary of any side effects you have. This will help you to clearly explain to your specialist team at your next review what side effects you had, and how long they lasted.

**CERDYN RHYBUDD CEMOTHERAPI CHEMOTHERAPY ALERT CARD**

**If you have side effects please follow the information on your alert card about when to contact us.**

Some side effects if not treated quickly can become life threatening.

Most side effects from chemotherapy are short lived and can be easily managed following advice from your specialist cancer team. Side effects which are reported early are usually much easier to treat.

**What to do if you get any side effects:**

This will depend on how severe they are. Side effects can be described as mild, moderate or severe. We have used the traffic light colours to highlight the severity of symptoms and the actions you should take:

**If you have chest pain or difficulty breathing CALL 999**

**Severe**

Call the 24 hour number on your alert card **NOW** for:

- any symptoms in the red column of the chart overleaf or
- any of the symptoms on your alert card

**Moderate**

Call the 24 hour number on your alert card for:

- Any of the symptoms in the amber column which are also on your alert card or
- If you need specialist advice to manage the symptoms

**Mild**

Follow the advice in your chemotherapy information leaflets or if you need advice about managing the symptoms contact your specialist nurse/key worker or GP

V.1 2017

*An extract from the patient held information folder*

# One year on: working together on the New Treatment Fund in Wales

Thanks to the Welsh Government’s £80 million New Treatment Fund, patients are benefiting from collaborative efforts to improve access to the very latest medicines, no matter where they live or what their disease may be.

Last year, the ABPI **welcomed** the Welsh Government’s commitment to strengthening financial and infrastructure planning to speed up Welsh NHS patients’ access to the very latest medicines. The £80 million New Treatment Fund meant a new, collaborative approach to horizon scanning for innovative medicines in Wales.

Now, one year on, it is good to see the impact that the Treatment Fund in Wales has had in providing focus for all stakeholders in the healthcare sector to work together to ensure that patients across Wales benefit from access to life-changing medicines in a planned and timely fashion.

There is a clear commitment across Wales to improve horizon scanning to more effectively anticipate the arrival of innovative, evidence-

based treatments – and identify those treatments that enable new approaches to care, change patient care pathways or have significant resource implications.

As Industry, we have worked together with colleagues from across the Welsh Government, NHS Wales and our members to support the New Treatment Fund. The ABPI has accepted the challenge laid down by the Cabinet Secretary for Health and Social Services to support the ability of Health Boards to horizon scan: improve their financial forecasting and infrastructure planning.

Since the launch of the New Treatment Fund in January 2017, we have also commissioned a **new report** from the Wales Institute of Health and Social Care (WIHSC), University of South Wales, which

outlines the potential contributions from individual stakeholders, and highlights the clear benefits to the system if horizon scanning is co-ordinated and developed collectively.

As we look ahead, the ABPI continues to encourage all stakeholders to work with us to reap the clear patient and health system benefits from working collaboratively.

Strengthening financial and infrastructure planning makes sense for everyone, with health boards benefiting from improved forecasting, the industry benefiting from early use of their innovative treatments and – most importantly – patients benefiting from faster access to evidence-based medicines. Working together, we can make this happen.

1 Royal College of Radiologists: Clinical Oncology workforce: the case for expansion 2014 [https://www.rcr.ac.uk/sites/default/files/u21380/BFCO\(14\)5\\_CO\\_workforce.pdf](https://www.rcr.ac.uk/sites/default/files/u21380/BFCO(14)5_CO_workforce.pdf)

2 South Wales Cancer Network: Guidance Document for Systemic Anti Cancer Therapy (SACT) Services (2015)



## Janssen, Welsh Government and NHS Wales Joint Working Initiative

**Welsh Government and NHS Wales wish to support increased joint working with industry, focused on delivering better outcomes for people in Wales, by improving the efficiency and effectiveness of services, in line with the principles of 'Prudent Healthcare'.**

There has been rapid therapeutic advancement in the treatment of myeloma in recent years, which has improved patient outcomes. However, novel agent therapy comes at a high cost and long-term treatment of myeloma, which remains a chronic incurable malignancy, remains highly challenging. The aim should be to maximise patient longevity and quality of life through minimisation of the short- and long-term damage incurred by both the disease and the medicines used to treat it. This requires scrutiny of patient disease burden and fitness at diagnosis, together with response to treatment and its impact in terms of quality of life. This can only be achieved through systematic data capture throughout the patient journey.

Motivated by a desire to move from a transactional approach to a partnership between Janssen and the NHS, this project can be thought of as 'commissioning for outcomes'. This is where investment by pharmaceutical companies in the health sector can take the form of both the means to access novel therapies early in their development, alongside support for resources, which will make these agents more cost effective and feasible to deliver. It was identified that haematology services in Wales require an innovative and personalised

database which can critically analyse the outcome data for patients with myeloma and eventually all other haematological malignancies. As such, units should have access to a database registering all patients at diagnosis with data regarding their demographic features, disease presentation/staging, diagnostic features, treatment plan, response to treatment and overall survival. Quality of life data may also be collected, both to justify the cost and burden of treatment and to demonstrate the impact of treatment over non-treatment from a patient perspective.

Historically data capture for cancer patients in Wales has been through the Cancer Network Information System Cymru (CaNISC) system. Designed for solid tumours, it is ill equipped to capture the nuances of haematological diseases. It also is not suitable for the requirements of quality of life data capture or treatment response. This unscrutinised treatment with high-cost, potentially toxic drugs has inevitably led to wasted resource and ineffective treatment for some patients. Investment in data capture is urgently required to reverse this trend.

The key benefit of implementing a Welsh haematology database is

being able to measure the impact of treatment on patient outcome and quality of life, and to justify costs. For the first time, it will accurately record detailed information on incidence, treatment and survival rates from myeloma and subsequently all haematological cancers across Wales. This will enable NHS Wales and the Welsh Government to consider the outcomes for approved medicines, making informed decisions about which treatments to invest in – or stop funding. In addition, patients can be provided with a more honest assessment of what to expect from treatment pathways based on real-world evidence data.

The database will also potentially give the Welsh Government the opportunity to gain access to medicines ahead of other UK countries, as pharmaceutical companies will be drawn by the incentive of efficient data capture. By having a robust system in place that will allow pharmaceutical companies to propose patient access schemes, NHS Wales and the Welsh Government will have the data available to make an informed decision on what is best for patients in Wales and ensure they are getting access to the best medicines, at the best price, as early as possible.

*Main Image: Launching the new initiative (l-r): Vaughan Gething, AM (Cabinet Secretary for Health and Social Services), Nicky Lilllott (Senior Director, Government Affairs & Policy, UK and Ireland, Johnson & Johnson), Lee-Ann Farrell (Government Affairs Manager – Wales & Northern Ireland, Janssen-Cilag Ltd), Mark Hicken (Managing Director, UK & Ireland, Janssen-Cilag Ltd) and Ken Skates, AM (Cabinet Secretary for Economy and Transport)*

# Pfizer and Swansea University drive forward collaboration at BioWales 2018

**Pfizer and Swansea University are driving forward their vision to improve health and wellbeing for the people of South West Wales; delegates at this year's BioWales conference were told earlier in March.**

This will include a range of therapeutic and technology-based interventions, which will be studied through the collection of real-world data. The aim of the hub is to share knowledge, skills and expertise to develop a health system that works with industry, the NHS and academia to improve healthcare in this region.

During his keynote address, Professor Marc Clement, Vice-President of Swansea University, told BioWales that the first phase of the collaboration would see the creation of two new roles to drive the project forward. Co-funded through the partnership, the Innovation Hub is recruiting a Professor of Enhanced Health Innovation, Engagement and Outcomes, as well as a Digital Technical Consultant. He went on to highlight that the high-profile collaboration will also help deliver elements of the £1.3billion Swansea Bay City Region City Deal. Professor Clement said:

*“One of the aims of the City Deal is to create a ‘living laboratory’ in this region for health, wellbeing and life sciences. This regional vision is strongly aligned with the UK Government’s recent Life Science Industrial Strategy. We see this collaboration with Pfizer as a real opportunity to operationalise our vision and aims with purpose and pace. We will be working with our colleagues at Swansea University’s Medical School and two local health boards to develop a ‘test and learn’ model to deliver projects which can be scaled up and adopted across the region, Wales and the rest of the UK at pace. The Llanelli Wellness and Life Science Village will be one of the first examples of this work.”*



*Erik Nordkamp, Managing Director, Pfizer UK and Professor Marc Clement, Vice-President of Swansea University at BioWales2018*

Managing Director of Pfizer UK, Erik Nordkamp added:

*“We are delighted to have formalised our strategic partnership with Swansea University and look forward to working together to share knowledge and experience. Our aim is to develop innovative approaches to improve patient outcomes, support long-term sustainability of the NHS and maintain a thriving life sciences industry in the UK. With Swansea University, we recognise South West Wales as a region with the potential to be at the forefront of excellence in healthcare service delivery, research, education and innovation.”*

Mr Nordkamp said the City Deal project at Delta Lakes in Carmarthenshire would bring all these factors together in one place:

*“The creation of the Llanelli Wellness and Life Science Village will provide a unique setting to test, capture, develop, prove and embed new ways of working and thinking.”*

*We are excited for the future of this partnership and the opportunity it represents for current and ongoing collaboration between industry, the Government and the health system to put patients first.”*

A Pfizer-commissioned report by PwC, *Driving Global Competitiveness of the UK’s Life Sciences Ecosystem for the Benefit of UK Patients, the Economy and the NHS* underlines the importance of collaboration. It asserts that workforce and skills, academic and leading-edge science along with access to medicine are the three most important factors in achieving the UK’s ambition for a thriving and globally competitive life science sector. Professor Clement stated:

*“Pfizer is one of the world’s largest research-based biopharmaceutical companies. Being able to attract such established, innovative international companies to partner with us is a sign of confidence in this region and our ambition.”*

# Horizon scanning and planning for the future: New medicines and NHS Wales – Dr Rick Greville writes ...

The better you understand what is heading your way, the better you can prepare and plan for the future. Identifying and planning for the availability of new innovative medicines and treatments in the pharmaceutical pipeline is no different.

With the average development, licensing and regulatory-cycle for a medicine taking in excess of twelve-years, proposed medicines' launch dates are inevitably uncertain – whether through welcome acceleration, unfortunate delays or catastrophic termination during the clinical trial phase.

On announcing the *New Treatment Fund in 2017*, the Cabinet Secretary for Health and Social Care in Wales, Vaughan Gething AM, challenged the pharmaceutical industry to support improved horizon scanning by NHS Wales, especially to identify where infrastructure and/or service reconfiguration may be required to support the introduction of a new medicine.

As ABPI Cymru Wales, we responded to this challenge by improving our understanding of the current horizon scanning processes in Wales, collaborating across industry and the wider health sector to identify good practice approaches.

In 2017, we invited our European colleagues from *EFPIA* to participate at the *Welsh NHS Confederation Conference* and the *Bevan Commission Annual Conference*, where they outlined

the challenges faced across Europe in long-term horizon scanning and opportunities, from early identification of transformative treatments in a number of disease areas, including Alzheimer's and cancers.

However, we also recognised the need for a non-partisan view of horizon scanning and planning needs and, following earlier work undertaken in 2014 and 2016, the ABPI re-commissioned the *Welsh Institute for Health and Social Care (WIHSC)*, *University of South Wales* to explore the issues around horizon scanning in Wales and elsewhere.

WIHSC focused their work on understanding how different nations undertake horizon scanning, through individual interviews and a workshop, where the approaches were considered through the eyes of NHS Wales, the Welsh Government, the All Wales Toxicology and Therapeutics Centre (AWTTC) – the secretariat to the All Wales Medicines Strategy Group (AWMSG) – and ABPI member companies.

All participants were clearly committed to improving horizon scanning in order to more effectively anticipate the arrival of new medicines – and clearly identify those that may



Dr Richard Greville  
Director Wales & Director  
Distribution & Supply, ABPI

enable new approaches to care, change patient pathways or have significant resource implications.

*A new report from WIHSC* captures potential individual contributions from the quartet of stakeholders, but usefully also captures the clear benefits if horizon scanning contributions and approaches are co-ordinated and developed collaboratively.

WIHSC suggests that the development of a Wales Advanced Notification (WAN) process could be such a collaboration project – ensuring an approach to horizon scanning which is “Once for Wales”, but sits usefully alongside other UK-wide approaches such as UK PharmaScan.

It is clearly important that all stakeholders continue to work collaboratively on this topic to ensure that patients across Wales benefit from access to new, innovative medicines in a planned and timely fashion. We are inviting everyone, from NHS Wales, the Welsh Government and patient organisations, to ABPI members and other companies in the pharmaceutical industry, to get involved. For more information, contact *ABPI Wales*.

## Brexit Health Alliance – Impact of Brexit on patient access to medical research

**At the end of February, the Brexit Health Alliance released a new report on the impact of Brexit on patient access to medical research.**

The timing was pertinent given recent questions at the National Assembly for Wales on this matter. As a member of the Alliance, the Association of the British Pharmaceutical Industry (ABPI) have supported the development and content of the briefing.

A summary, the press release and policy briefing are all available via

<http://www.nhsconfed.org/regions-and-eu/nhs-european-office/brexit/brexit-health-alliance/patient-access-to-medical-research>



*Coffee Shop Meetings / Jack Sargeant AM meeting with members of ABPI Cymru Wales Industry Group*

## Meet ABPI Cymru Wales

**Following the success of our “Meet ABPI Cymru Wales” sessions held in 2016 and 2017, we re-ran the exercise on 6 and 7 March 2018.**

Representatives of the ABPI Cymru Wales Industry Group based themselves in the coffee shop at the Senedd, meeting Assembly Members and their staff. This offered everyone involved the opportunity to have an informal discussion on some of the key issues facing the pharmaceutical industry's work in Wales. Amongst other areas, we discussed the New

Treatments Fund, horizon scanning (advanced planning) for new treatments and the implications of Brexit for Wales.

We would like to take this opportunity to thank those who took the time to come and speak with us. As ever, if an Assembly Member – or their team – would like to meet with the ABPI and its members, please get in touch!

## Who we are

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. We represent companies who supply more than 80 per cent of all branded medicines used by the NHS and who are researching and developing the majority of the current

medicines pipeline, ensuring that the UK remains at the forefront of helping patients prevent and overcome diseases.

Globally our industry is researching and developing more than 7,000 new medicines.

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.

For further information about any of the issues in this Bulletin or about ABPI Cymru Wales, please contact:

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Bringing medicines to *life*  
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