

Why does availability of new medicines depend on access to health data?



In May we held a drop-in session at the Welsh Parliament to talk to Senedd Members and their staff about the importance of health data to industry and the NHS, and how this enables patients to benefit from the most effective new medicines.

Access to anonymised health data is essential for the research and routine use of safe and effective medicines, as it underpins all stages of the medicines' development, and deployment process - from early-stage research, through to the long-term safety monitoring and targeted prescribing of innovative and life-saving treatments.

Health data is used by our members in the pharmaceutical industry to support a wide range of essential activities which benefit patients, including:

- understanding disease progression and outcomes
- conducting clinical trials
- making regulatory authorisation submissions to the Medicines and Healthcare products Regulatory Agency (MHRA)
- applying to the All Wales Medicines Strategy Group (AWMSG) and National Institute for Health and Care Excellence (NICE) for approval to be used in the NHS, and
- demonstrating the safety and effectiveness of an approved medicine, once in routine care

Wales has a wide range of health datasets that can offer great insights into conditions where there are currently no, or limited, effective treatments.



In contrast to some other parts of the UK, it is difficult for the pharmaceutical industry to access anonymised health datasets in Wales.

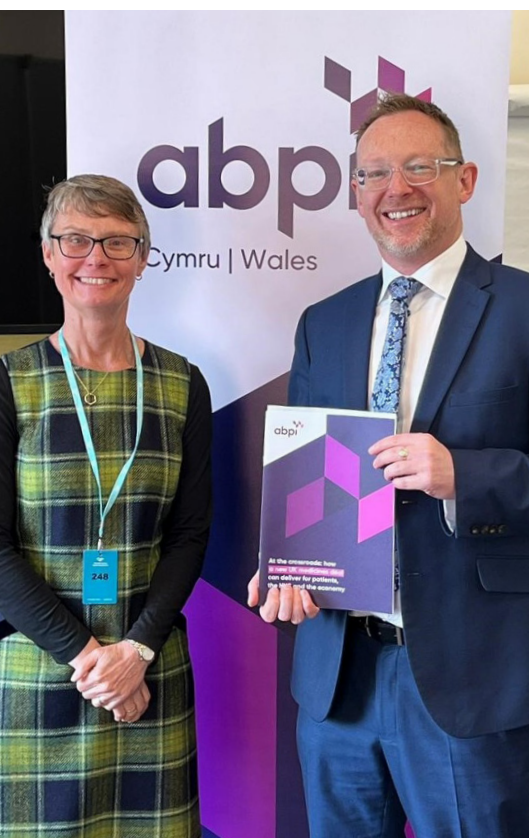
As a result, Wales may be missing out on industry research and development (R&D) investment. More importantly, Welsh patients are under-represented in UK patient datasets that are routinely used by regulators and industry to understand how people could benefit from new treatments and to evaluate a medicine once it is in use in the NHS.

The pharmaceutical industry is one of the most tightly regulated industries in the world and has decades of experience in responsibly and securely handling and analysing health data. ABPI members recognise the importance of data governance and respecting patient confidentiality¹. Implementation of the new Welsh digital health strategy offers enormous opportunities, which would be enhanced if the pharmaceutical industry were able to securely access anonymised health data to improve the health outcomes of Welsh patients and the efficiency of the Welsh NHS.

Negotiations for the next 5-year medicines voluntary pricing scheme have started and as part of this next Voluntary Pricing, Access, and Growth scheme (VPAG), the pharmaceutical

industry is proposing an additional £1bn funding for an investment facility to benefit the wider UK life sciences ecosystem. A key component of the proposed investment facility is industry funding for data infrastructure to facilitate patient recruitment into clinical trials across the UK.

The benefits that clinical research brings to patients are well evidenced, with research-active hospitals delivering lower mortality rates as well as improved patient confidence in the care they receive. Secure access to Welsh health data, within the proposed safe health data recruitment service, will be essential for Welsh patients to have increased opportunities to participate in clinical trials, in common with patients across the rest of the UK.



¹ <https://www.abpi.org.uk/publications/principles-for-analysis-and-use-of-health-data-by-abpi-members/>

What is Genomics and why is it important for the future of healthcare?

In June, we collaborated with Genetic Alliance UK on a drop-in session at Senedd Cymru to talk about genomics – what it is, and why it is important for the future of healthcare.



Genomics is the study of the genome, the complete set of genetic information contained within DNA. This set of information is repeated within almost every cell, determining its function and influencing the growth, development, and workings of the entire body. DNA contains coding regions made up of units called genes, with each gene providing the information needed to make a protein – the component parts that create the body's structures like lungs or skin and perform the processes needed for them to function. DNA also contains non-coding regions, which help to regulate how genes function.

The variation between people in anything from eye colour to blood type is determined by the differences in an individual's genome, or genetic make-up. This variation can also determine the presence or absence of disease. Genetic variations may cause disease by providing incomplete or wrong 'blueprint' information for building proteins which consequently do not function properly. A person with these types of variations in their DNA is either born with the associated disease or may develop the disease during their life. An individual's genome can also be changed by exposure to various environmental factors over the course of a person's life, influencing disease development and progression.

There is huge potential for genomics to benefit patient care right across various diseases, from rare disease to cancer. By studying genomics, we can learn more about how and why some diseases are caused. This can be harnessed in research to identify new targets for medicines, providing the basis for the discovery of new treatments. Understanding more about how a disease develops can also help predict who is at most risk, so that preventative approaches can also be targeted and put in place as early as possible. Genetic variation also affects the way each person responds to a treatment – how effective it will be, or whether it might cause adverse effects. Knowing this can help select the best medicine or the correct dose and avoid/minimise potential side effects.

In Wales, the All Wales Medical Genomics Service (AWMGS)² provides specialist genetic services to individuals and families with, or concerned about, rare genetic conditions. The service is made up of clinical genetics and laboratory genetics, with specialties covering haematology, neurology, cancer genetics, oncology, rare diseases, pre-natal, pathology and pharmacogenomics³. The Welsh Government and the Welsh Health Specialised Services Committee (WHSSC) agreed in April 2019 to expand the genomic testing available for patients and their families with rare diseases, with increased funding aimed at improving patient care in Wales⁴.

² All Wales Medical Genomics Service. Home [Internet]. 2022 [cited 2022 Sep 28]. Available from: <https://medicalgenomicswales.co.uk/>

³ All Wales Medical Genomics Service. Which genetic test do you require? [Internet]. 2022 [cited 2022 Sep 28].

Available from: <https://medicalgenomicswales.co.uk/index.php/health-professional-information/a-z-of-services>

⁴ All Wales Medical Genomics Service. Constitutional Rare Disease Services [Internet]. 2020 [cited 2022 Sep 28].

Available from: <https://medicalgenomicswales.co.uk/index.php/about/constitutional-rare-disease-services>

Genetic Alliance UK

Genetic Alliance UK is the largest alliance of organisations supporting people with genetic, rare, and undiagnosed conditions in the UK. A key part of their work is to advocate for fast and accurate diagnosis, good quality care, and access to the best treatments.



Genetic Alliance UK recognises that recent advancements in cell and gene therapies can now offer a potentially life-saving option for some people living with genetic conditions or cancers. However, it is important that people who may benefit

from these treatments, and the wider public, have a good understanding as to what these therapies are. As part of their work, the Alliance has launched a new [Cell and Gene Therapies magazine](#).

The Drop-In offered an opportunity for Genetic Alliance UK representatives to discuss this new development – and the role that the recent advancements in cell and gene therapy could have for some of their members.

How AWMSG and AWTTTC are supporting sustainability for the NHS in Wales

The All Wales Therapeutics and Toxicology Centre update on their work on sustainability

The [Well-being of Future Generations \(Wales\) Act \(2015\)](#) is ground-breaking legislation that aims to ensure that future generations in Wales have at least the same quality of life as we do now. Public bodies in Wales, including the All Wales Medicines Strategy Group (AWMSG) and the All Wales Therapeutics and Toxicology Centre (AWTTTC), have a legal duty to take into account the impact that their decisions will have on future generations. AWMSG and AWTTTC have committed to a [sustainability pledge](#). AWTTTC has set up a Sustainability Group to support AWMSG to consider the Act's 'sustainable development principle' in its decision making.

A report, "[AWMSG and the Well-being of Future Generations \(Wales\) Act](#)" (2022), outlines how AWMSG and AWTTTC are working to achieve the act's seven well-being goals through four well-being objectives. The report emphasises the importance of communication and collaboration with stakeholders, including the pharmaceutical industry, to reach those goals.

Helping the NHS in Wales to reduce its carbon footprint

A national strategy to reduce the carbon footprint of inhalers in Wales

is currently going through AWMSG's endorsement process. It outlines key actions for the NHS to follow and emphasises a commitment to collaborate with a range of stakeholders, including the pharmaceutical industry, to achieve this aim.

AWMSG prescribing guidelines support sustainability

In December 2021, AWMSG endorsed prescribing guidelines that aim to reduce variation in inhaler prescribing in Wales, for the management of [adult asthma](#) and [chronic obstructive pulmonary](#)

[disorder](#) (COPD). Prescribing guidelines for managing [paediatric asthma](#) were endorsed in May 2023. These guidelines encourage consideration of the [NHS Wales decarbonisation strategic delivery plan](#) and recommend preferential prescribing of dry powder inhalers (DPIs) and soft mist inhalers (SMIs), rather than metered dose inhalers (MDIs). This aligns to the target for the NHS in Wales to reduce MDI use from more than 70% of inhalers prescribed to less than 20% by 2025.

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AWTTC decarbonisation dashboard – reporting progress in decreasing the carbon footprint of inhalers in primary care in Wales

AWMSG and AWTTC think about the long term impacts of what they do, as one of their four well being objectives. They have developed a decarbonisation dashboard to show the carbon footprint from the use of inhalers issued in primary care in Wales. The dashboard has:

- data on health board, cluster, and GP practice prescribing
- data on the carbon footprint and money spent on inhalers available for prescribing within Wales
- a switching tool, to help prescribers help patients make the change to using a DPI

Data show an upward trend from Spring 2022 in use of DPIs and SMIs as a percentage of total items from Spring 2022 across most Welsh health boards. This followed the endorsement of the updated prescribing guidelines for managing adult asthma and COPD in December 2021 (see Figure 1 below).

This shows how quickly the work of AWMSG and AWTTC can influence prescribing practices in Wales, and the importance of being able to capture the impact of this decision-making through data collection. The dashboard is currently available to all NHS staff on the Server for Prescribing Information Reporting and Analysis (SPIRA), with monthly summary reports generated that are available for the public to see on the AWTTC website.

AWTTC Pinboard

- **Please save the date: 30 November 2023**, for this year's AWMSG Open Day at the All Nations Centre in Cardiff. Flyer to be circulated with registration information.
- **Blueteq update:** The NHS Wales Blueteq Implementation Steering Committee are supporting a review of Blueteq forms in several therapeutic areas. They aim to launch a limited number of pilot schemes within selected health boards over the coming months. An AWTTC Project Manager will attend ABPI's October meeting to update on progress.
- **Medicines access:** We have recently shared a document on the AWTTC website, 'Review of AWMSG processes to support medicines access in NHS Wales', which provides an overview of the challenges faced by AWMSG as the medicines access landscape across the UK changes. The document outlines a proposal on how AWTTC may adapt their processes to ensure routes of access are suitable for the needs of the NHS in Wales. The next phase of this work will incorporate a consultation with our key stakeholders.



AWTTC
All Wales Therapeutics & Toxicology Centre
Canolfan Therapiwteg a Thocsicoleg Cymru Gyfan



Grŵp Strategaeth Meddyginiaethau Cymru Gyfan
All Wales Medicines Strategy Group

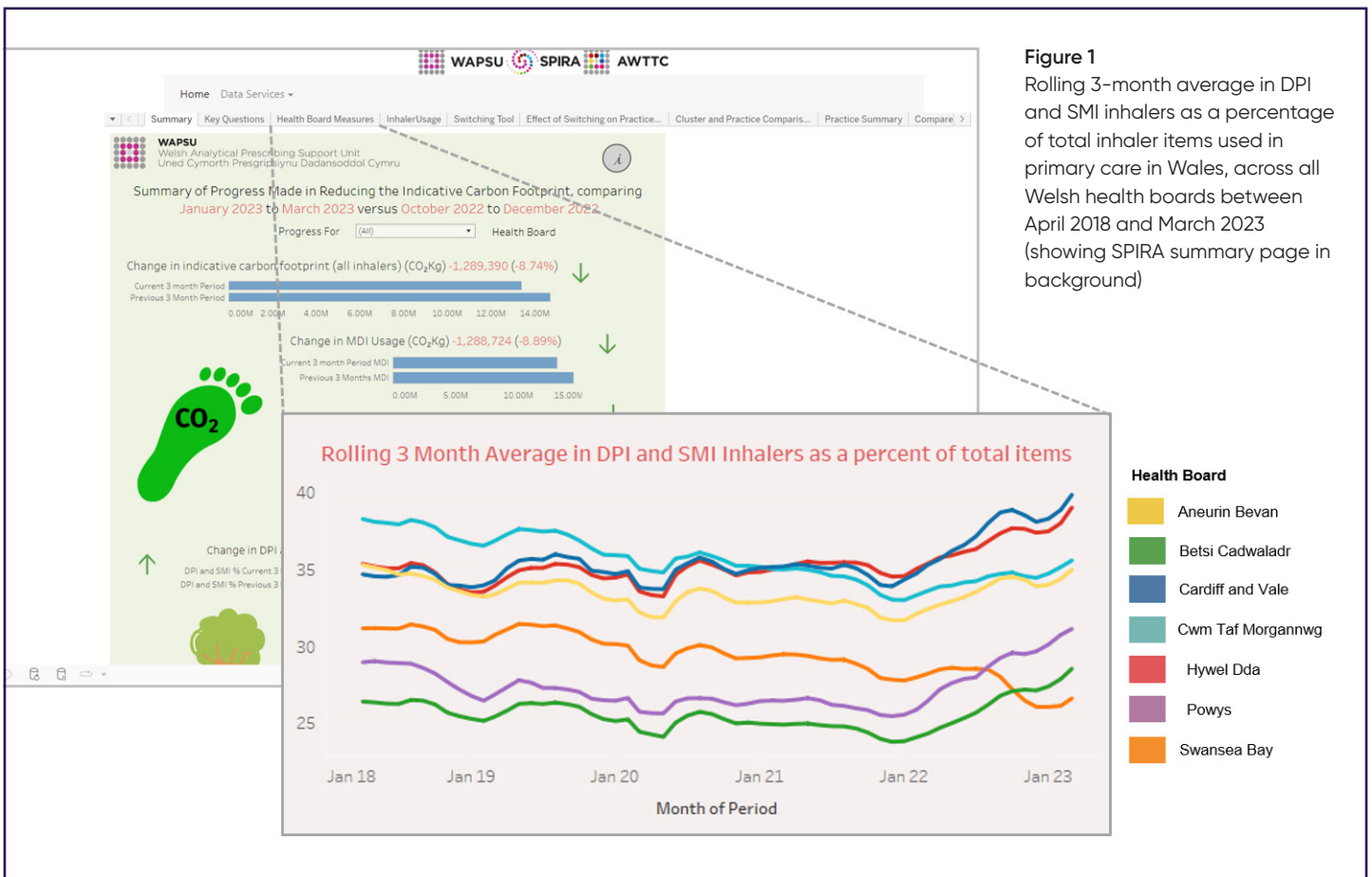


Figure 1
Rolling 3-month average in DPI and SMI inhalers as a percentage of total inhaler items used in primary care in Wales, across all Welsh health boards between April 2018 and March 2023 (showing SPIRA summary page in background)

ABPI Cymru Wales Jargon Buster

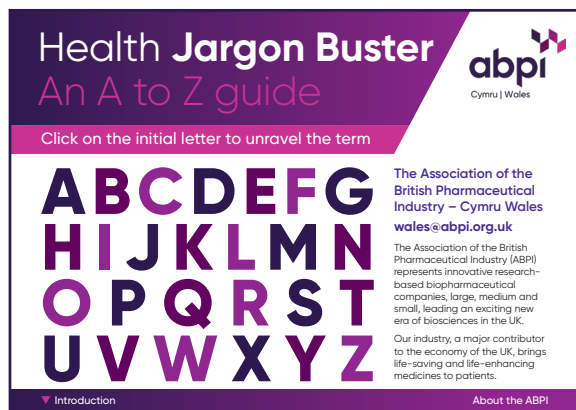
Those of us who primarily work in healthcare spend a lot of time thinking about health

literacy. Enabling people to make informed decisions about their care and treatments is fundamental to maintain and improve individual – and

We started producing our Health Jargon Buster back in 2016. It was originally intended for our new cohort of then Assembly Members that year, to help them through the inevitable steep learning curve as they took on new responsibilities. It was a cleverly designed fold-out card, and proved very popular. Fast forward to 2021, and that card in mid-pandemic was no longer viable and we moved online. This allowed us to provide links – so now, not only could the reader work out what the acronym meant, but also find out more in one easy click. Whilst we missed the little card that was a constant companion for many, our phones and tablets are now omnipresent – and so is our Jargon Buster!

With the health environment continuing to change, we've now updated the [ABPI Cymru Wales Health Jargon Buster](#) and it's now available online.

Please feel free to share this resource, particularly with colleagues who may be afraid to ask why the AWMSG works with AWTTTC on HTA! and if you have any ideas as to how it can be improved, let us know.



population – health. However, we sometimes forget that colleagues and stakeholders may not always be as 'deep in the weeds' of healthcare jargon. In Wales we love nothing more than an acronym, and that got us thinking. How much of what we say is being understood?

Bevan Commission launches the Let's Not Waste Programme

Simon Devitt, Let's Not Waste Programme – Project Manager, introduces their work.

Waste is an invisible scourge in health and social care, whether it is material resources, time, opportunity, energy, or a myriad of other things. How often are great ideas ignored, lights left turned on, outdated practices maintained, or single use materials discarded in your line of work? No matter where we find waste in the sector, it is always at the expense of our communities and those we try to help.

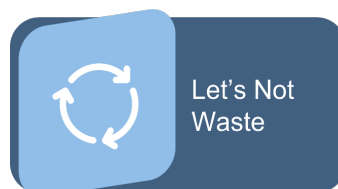
In recognition of this often-misunderstood issue, the Bevan Commission has launched Let's Not Waste – a national programme which will bring together health and care professionals from across services, to identify and mitigate waste in the sector.

Membership of the Let's Not Waste collaborative network is open to anyone interested in playing an active role in reducing waste in the health and care sector in Wales. By signing up to Let's Not Waste, you will be joining others in forming the Let's Not Waste network. To learn more and sign the pledge, please visit: www.bevancommission.org/lets-not-waste

The programme was launched in April with a webinar attended by 220 health and care professionals, and guest speakers with expertise in the field: Professor Sir Don Berwick, Professor Sir Andy Haines, and Dr Richard Smith. These speeches are available [here](#).

To set out the importance and urgency of this work, the Bevan Commission has published a new paper 'What A Waste', which calls for a focus on the problem of inappropriate waste in the delivery of health and social care in Wales and action to address it. This paper is available [here](#).

The Bevan Commission hopes that by coming together, Wales can set an example for a health and social care sector that uses every resource wisely and, in doing so, delivers excellence for service users and the environment.



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