

Cross Party Group on Medical Research

Wednesday 30th April 2025, 12.00-13.00

Microsoft Teams

Advanced Therapies Wales

MS' in attendance:

- Russell George MS (RG)

Other attendees:

- Bronwen Morgan-Jones, BHF Cymru (BM-J)
- Bethan Edwards, BHF Cymru (BE)
- Rachel Savery, Advanced Therapies Wales (RS)
- Jemin Popat, patient representative (JP)
- Joanne Castle, ABPI
- Anton Saayman, HEIW
- Jo-Ann Baker, Cardiff University
- Mark Briggs, Cardiff and Vale UHB (MB)
- Corinne Squire, Cardiff University
- Lynne Grundy, BCUHB
- Thomas Brayford, Brain Tumour Research
- Nigel Rees, Welsh Ambulance Services
- Nicolas Webb, RCGP
- Jonathan Moore, Bangor University
- Hannah Bertie, HCRW
- Stephen Bain, ABM ULHB
- Rhian Thomas-Turner, Noah's Ark Children's Hospital for Wales

Minutes

1. Welcome and introduction

Chair welcomed attendees to the meeting, introduced the topic and the first speaker Rachel Savery, the Head of Programme for Advanced Therapies Wales.

2. Rachel Savery's Presentation

Rachel thanked the chair for inviting her to speak at the meeting. She started by giving some context and background to the programme.

Advanced Therapies sits alongside the Genomics Partnership for Wales pathology and imaging programmes.

There are two working groups which sit under the programme; one that focuses on research, development and innovation, and the other focuses on adoption.

In January this year, they completed a delivery plan which is the first in the UK.

There is evidence and treatments coming through which show these Advanced Therapies can be either curative or lifesaving because they often treat the root cause of the disease.

This is a real window of opportunity not just for the patients but for staff who are excited about the ability to be able to provide these treatments.

Some of the disadvantages of these therapies are that there are very high up-front costs. There are lots of unknowns, including the long-term side effects and efficacy. The current infrastructure is not quite joined enough to be able to access and deliver the therapies to patients.

There is a huge number of organisations who are invested or considering how Advanced Therapies are developed. The programme is trying to consolidate and provide a central coordinating centre to bring conversations together.

The programme has developed a five-year delivery plan. Goal one is around nurturing the ecosystem in Wales for Advanced Therapies. Goal two is focused on how these pathways are developed and delivered. Goal three is around increasing research capability and capacity, providing the space for research to occur and provide the interface for people to work together. Goal four centres on the programme being the central provision for information navigation and helping people find opportunities and information in this space.

The patient and public involvement is a key element the programme is pushing forward.

Advanced Therapies are increasing, there are 14 already approved by NICE for delivery to patients in the UK and there are more coming. There is therefore a need to equip the workforce better to deliver these services.

RG thanked RS for her presentation and introduced the next speaker, Jemin Popat. Jemin has an inherited blood disorder which leads to a reduction in the production of red blood cells.

3. Jemin Popat, patient representative

JP thanked the chair and started his presentation with an overview of his condition, thalassemia, and experience growing up.

The treatment in the short term is blood transfusions but this causes the body to have too much iron which then must be treated. In many other countries, children with thalassemia don't live past their teen years.

Some of the symptoms of the condition JP experiences includes a compressed spin, chronic back and leg pain, loss of hearing and eyesight.

JP takes 6 tablets a day to treat his condition.

There are around 9 people in Wales with this condition and 400 across the UK.

This new treatment can cure thalassaemia but it is very expensive and complicated. To receive the treatment, JP would have to go through rigorous chemotherapy in a hospital in London, meaning time away from his young son and family. The chemo could also give him leukaemia later in life. JP expressed his fear of going through chemotherapy.

56 patients have gone through the treatment globally, and 56 people have been cured.

This treatment is quite England centric. Patients in London have been referred but no one yet in Wales.

Over the course of JP's life, he has had 900 blood transfusions, 2,500 hospital visits and endured 8000 needles.

4. Q&A

RG thanked the speakers for their presentations.

RG asked, "what do we need to be asking from Welsh Government from your perspective?" to both Rachel and Jemin.

JP response: we need to have that link with England because a lot of stuff comes through there. A lot of trials are in London and a lot of the newest information. We need to allow Rachel and other teams to connect better with England so we don't lag behind. There is a knowledge gap and we need to make sure it is as small as possible. Secondly, there is one doctor who looks after the 9 patients across Wales but he can only spend 0.2% of his time with them. He's fantastic but doesn't have enough time to write the referral letters and send the patients on the tests they need. There is also a knowledge gap within Wales, between north and south.

RG thanked Jemin for his response and turned to Bronwen and Mark to ask their questions.

BM-J asked what is the main barrier in tackling the implementation gap and how do we improve implementation?

MB asked JP what the main influencing factors were in his decision whether or not to undertake the treatment?

JP response: For Bronwen, the implementation gap goes back to the doctor. If the doctor in Wales was full time he would be able to go to London more and figure out the next steps. In answering Mark's question, JP remarked that some patients aren't strong enough for the chemo and others don't want to go through it. The treatment also makes you infertile so that's a key consideration. For some there is an identity issue because they don't know how to be without thalassaemia or what their life will look like after.

RS commented on these questions, highlighting that Welsh Government needs to capitalise on this investment and be brave in this space. We need to look at using the opportunities of these new therapies to be able to solve some of the current NHS challenges.

RG thanked Rachel and summarised some of the action points which is improving the links with the English NHS and exploring links around the investment.

5. AOB

RG highlighted that the next meeting will be in July which BE and BM-J are working on in the background and there is a Senedd event in September.

BM-J responded saying the event will take place on the 23rd September with ABPI and will be similar to last year where researchers can showcase their research on stands for free.

Chair brings the meeting to a close.

The meeting ended at 12.51pm.