

Medical Research and Kidney Joint Cross Party Group

Wednesday 18<sup>th</sup> June 2025, 12.15-13.15

Microsoft Teams

V-PAG

**MS' in Attendance:**

- Russell George, MS (RG)
- Mike Hedges, MS (MH)

**Other Attendees:**

- Bronwen Morgan-Jones, BHF Cymru (BM-J)
- Bethan Edwards, BHF Cymru (BE)
- Ellis Smith, Senedd support staff
- Ryland Doyle, Senedd support staff
- Kirsty Rees, Senedd support staff
- Joanne Popham, Popham Kidney Support
- Nicola Williams, HCRW (NW)
- Sian Griffin, Cardiff and Vale UHB (SG)
- Andrew Carson-Stevens, primary care speciality lead (AC-S)
- Amelia Lincoln, BHF Scotland
- Owain Brooks, Swansea Bay UHB
- Nicholas Webb, RCGP
- Cari-Ann Quinn, Life Science Hub Wales
- Linzi Quinn, Kidney Care UK
- Ella Davies, CRUK
- Kevin Carsley
- Felicity Waters, HRCW
- Corinne Squire, Cardiff University
- Mark Briggs, Cardiff and Vale UHB (MB)
- Lynne Orton,
- Selena Harris, GP
- Corrine Bell, Kidney Wales
- Thomas Brayford, Brain Tumour Research
- Jonathan Moore, Bangor University
- Ross Evans, Kidney Wales
- Stephen Riley, Cardiff University
- Hannah Bertie, HCRW
- Fiona Loud, Kidney Care UK
- Sacha Moore, Cardiff university
- Lynne Grundy, BCUHB
- Sarah Hurst-Williams, BCUHB
- Leah Mclaughlin, Bangor University

## Minutes

### **1. Welcome and Introduction**

Co-Chair Russell George, MS welcomed attendees and introduced the topic, voluntary scheme for branded medicines, pricing, access and growth. RG handed over to Nicola to start the presentations.

### **2. Dr Nicola Williams' Presentation**

Nicky thanked the co-chairs for the invitation to speak.

The UK Government and ABPI negotiated an investment programme for the next five years until December 2028. Of the £400m investment fund, Wales is to receive £22.1m. The majority of this fund will be directed to pioneering clinical trials and bolstering the NHS' capacity to deliver commercial clinical research. Within this there are two streams. The first focuses on expanding and enhancing existing dedicated commercial clinical research infrastructure across the UK, and the second on delivering flexible funding to pump prime clinical trial resources, by increasing workforce capacity and infrastructure.

Nicola handed over to Sian for presentation focusing on kidney research

### **3. Professor Sian Griffin's Presentation**

Sian thanked Nicola for the introduction and for the invitation to speak to the CPG about the importance of kidney disease and what a difference they can make, particularly with the VPAG funding.

There are many underlying causes which culminate in irreversible loss of kidney function, such as diabetes. There has been a 45% increase in the number of adults with diabetes in Wales over the past 15 years. It's the leading cause of kidney failure that results in people needing to start dialysis.

Treatments for kidney disease are both specific to the underlying cause and the more generic interventions that protect the remaining kidney function and stop progression to more advanced declines. The overall aim through treatments is to protect kidney function and avoid accelerated vascular disease.

There are 3.25 million people living with chronic kidney disease (CKD) in the UK, this is expected to rise to 3.9 million by 2033. Dialysis is extremely expensive, and the cumulative costs of these treatments account for about 3.2% of NHS budgets.

The CKD prevention lead at the Welsh Kidney Network has worked closely with primary care and on pharmacy led projects to ensure early intervention in treatment of kidney disease.

There are two areas of focus for upcoming research in kidney disease over the next 5 years; the first is in enrolling patients into generic studies to protect kidney function, and the other is on rare conditions.

Sian hands over to Andy.

#### **4. Professor Andrew Carson-Stevens' Presentation**

Andy is the primary care speciality lead at HCRW and is also a GP and professor of patient safety at Cardiff University.

Panoramic was a platform trial, which can be thought of as a disease focussed trial. Prior to this, recruitment for community-based research trials was incredibly low. Panoramic was an opportunity to make a substantive shift in this model. It allowed anyone in Wales to participate regardless of where they lived. They also used targeted messaging to reach typically underrepresented communities in clinical research.

The team also ran a trial in Cardiff called ComFluCov whereby people attending the Bayside mass vaccination centre for a Covid vaccine could get a flu vaccine in the other arm. Within 6 days, 128 patients had been recruited for the trial.

These projects through the One Wales approach, found that there are lots of primary care professionals, nurses and others who want to deliver research but lack the confidence to say yes.

With the VPAG investment they are going to motivate primary care to get that experience and build confidence to deliver trials within communities.

Wales must be ready to deliver this research with a supported, agile workforce to deploy these opportunities across Wales. The other part of the investment will help to grow capacity and capability of the workforce so we can build a reputation of Wales being a place of commercial research in the community.

#### **5. Q&A**

RG thanked the speakers and opened up the discussion to members for any questions.

BM-J asked the speakers to explain a bit more about the application process to get VPAG funding.

NW explained there is an external panel which reviews applications. There was a form people completed which demonstrated how they matched a key criterion, including whether they had a track record of commercial research delivery so that more studies could be attracted to Wales, whether there was a pipeline of studies open and available and whether they could demonstrate an element of USP in Wales.

MB asked whether the speakers feel confident that we've rewritten the clinical trials design playbook?

AC-S answered this question, arguing we are seeing a shift in culture and how studies/trials are designed across Wales with four university collaboration and conversations with key partners.

RG thanked Andy for his response and asked the speakers if there is anything MS' or Welsh Government could be doing ?

SG emphasised the importance of obesity and diabetes in public health and making sure this remains on Welsh Government's agenda. As a smaller nation, we have the ability to control educational policy and what information is given to young people.

AC-S suggested to maintain sustained investment in primary care, including supporting future pharmacists and dietitians.

BM-J asked how could VPAG investment in Wales attract more funding to medical research in Wales specifically?

SG said the limitation in Wales was not the number of patients, but the resource to screen and approach them to let them know about studies. The VPAG investment is going to lift the number of patients who are recruited into trials. The demonstration of success has previously attracted companies to Wales as a site for recruitment.

AC-S added that the VPAG investment will allow for the identification of effective ways to offer opportunities into communities, work across sectors and expand the capacity for Wales.

RG refers to Bethan Edwards and Mark Briggs to ask the final two questions.

BE asked for the speakers thoughts on involving patients in clinical trials and the barriers around this.

MB commented on how clinical trials are a global marketplace from a pharmaceutical perspective. The UK has a superb reputation, but we are in a competitive market so the ability to bolster resources and deliver high quality trials in a timely manner is massively attractive to pharmaceutical companies. If they've got confidence in our ability to deliver effectively at a competitive price point, then they will be back in droves – this is a first step to enabling that to happen.

SG highlighted that she has seen trials increase in accessibility slowly over the past 10-15 years and patients are more positive about being approached for clinical trials.

NW thanked BE and MB for their comments and linked them to the work of the HCRW comms team. Their work in raising public awareness of specific trials, HCRW and NHS Wales, as well as how to engage and sell Wales to the pharmaceutical industry and highlighting studies to potentially eligible patients is extremely important.

MH made some closing remarks, thanking the speakers for their presentations and reiterating the importance of obesity and type two diabetes.

## **6. AOB**

BM-J reminded members of the upcoming event in the Senedd in September to showcase medical research in Wales.

RG thanked everyone for attending and the speakers before closing the meeting.