Minutes of the Cross Party Group on Medical Research

1st December 2021, 12.15pm

Held online via Microsoft Teams

An attendee list is available on request from the CPG Secretariat

Item 1 Welcome and Introductions

Acting Chair, Russell George MS welcomed attendees and provided a short introduction to the past work of the CPG and the future terms of reference for the newly constituted group.

He thanked British Heart Foundation Cymru and Cancer Research Wales for their support to date restarting the work of the group post 2021 Senedd election. Before moving onto the following item, the formal AGM, proceedings were handed over to Greg Pycroft (Cancer Research Wales).

Item 2 AGM

Greg Pycroft conducted the election of a CPG Chair he invited nominations.

Nominee Proposed Seconded Russell George MS Sioned Williams MS Altaf Hussain MS

There were no further nominees, an election was not required, and Russell George MS was elected to the role of Chair. Proceedings were handed back to the Chair to conduct the election of the CPG Secretariat.

The Chair conducted the election of the CPG Secretariat and invited nominations.

Nominee Proposed Seconded Charlotte Joanne Ferris (ABPI) Morgan Altaf Hussain MS (British Heart Foundation Cymru) and Greg **Pycroft** (Cancer Research Wales) working partnership to provide a joint-Secretariat

There were no further nominees, an election was not required. British Heart Foundation Cymru and Cancer Research Wales were elected to jointly provide the Secretariat to the CPG on Medical Research.

Item 3 Presentation: Clinical research in the UK: an opportunity for growth

Jennifer Harris, PhD, Head of Research Policy The Association of the British Pharmaceutical Industry

The Chair introduced Dr Harris. He invited her to give her presentation containing the findings of <u>a recent ABPI report concerning clinical trials</u> in the UK (the presentation slides have been shared separately).

Item 4 The Patient's perspective

Julie Hepburn
Lead Lay Research Partner, Wales Cancer Research Centre

The Chair introduced Julie and invited her to offer her experience of medical research

Julie shared her cancer experience and how it influenced her interest and involvement in cancer research.

Julie felt that Wales needs a co-ordinated approach to cancer research, something she hopes the Wales Cancer Research Strategy will help deliver.

Julie spoke about the importance of Wales getting its fair share of research funding from UK Government; that there's good, competitive research careers for researchers to remain in Wales, and she noted the increasing importance of device and technology trials as they help improve patient outcomes, particularly patients with chronic conditions/comorbidities.

Item 5 The Patient's perspective

Lucy Dixon Chair, PCD Support UK

The Chair introduced Lucy and invited her to give her presentation (presentation slides have been shared separately).

Lucy introduced the CPG to the rare disease, Primary Ciliary Dyskinesia that she was born with and diagnosed with aged 4.

Due to its rare nature it is a disease without much research, but the research that has been undertaken has discovered PCD affects more people than previous estimates. Research will be the only way to improve outcomes for people with PCD.

All of the research into PCD is undertaken outside Wales. Lucy stressed that patient registries are really important to people in Wales, a means of accessing the sparse research opportunities that are available.

Item 6 Q & A

The Chair thanked all of the speakers for their contributions and invited questions or comments.

Lee Campbell (Cancer Research Wales) comment concerned perceived delayed recovery of some clinical trials at certain sites. Is it time for some sort of clinical trial roadmap in Wales?

Rhian Thomas-Turner (Cardiff and Vale UHB) asked several questions concerning how industry embeds into the NHS, so the latter better understands and is in a better position to benefit from products coming down the pipeline. She also asked about achieving better clinical trial design.

Dr Harris responded, the ABPI believes in a top-down/ bottom-up approach. Needs strong strategic direction and agenda at Board level; and colleagues being aware of the wider industry ecosystem. Industry spans nations/jurisdictions, can bring & share best practice from elsewhere. As far as clinical trials are concerned, we must shirt to new approaches – post-pandemic world needs us to do so. Explore what we do currently to unlock current, unused capacity. Think innovatively, utilise everything.

Keith Lloyd noted that pro-rata funding for research in Wales is 60% that of England and presents a barrier to opportunities unless investment from the Welsh Government is secured via Health and Care Research Wales.

Matthew Morgan stressed the importance of acute/critical care research, and that not enough of it is conducted in Wales. Wales has the lowest number of clinical academics in years; funding for research clinicians is down. Where does that come from?

Item 7 Actions & Next Steps

The Chair thanked everyone for their contributions, that would assist with informing the development of the CPG workplan. Any additional workplan-related comments to be directed to the Secretariat.

Copies of the minutes of the meeting will be circulated by the Secretariat.

The Secretariat will administer the registration of the CPG with the Senedd Commission.

The next meeting of the CPG will be communicated via the Secretariat.

The Chair drew the meeting to a close.

Meeting ended at 1.20pm