

Cross Party Group on Medical Research
First meeting of 2020

Second evidence session of the Inquiry: Charities

Thursday 9 July 2020

2pm, Online via Zoom

Chaired by Dai Lloyd MS

Minutes

Apologies

Paul Pavia, Insight Wales

Katie Chappelle, Stroke Association

Cari-Anne Quinn, Life Sciences Hub

Richard Greville, ABPI Cymru

Joe Ferris, ABPI Cymru

Sue Bale, Aneurin Bevan Health Board

Michaela John, Medical Genetics

David Davies, Royal College of Occupational Therapists

Nigel Rees, Welsh Ambulance Service Trust

In attendance

Dr Dai Lloyd AM, (DL) (chairing)

Presenting:

Andy Glyde, CRUK (AG)

Adam Fletcher, BHF Cymru (AF)

Mike Bryan, Angela Burns AM's Office

Bethan Edwards, BHF Cymru (BE)

Emma Henwood, BHF Cymru (EH)

Louis Mertens, Royal College of Psychiatrists Wales (LM)

Alexander Smith, Stroke Association Postgraduate Fellow

Mathew Norman, British Lung Foundation & Asthma UK

Lee Campbell, Cancer Research Wales (LC)

Ann Tate, Cancer Research Wales

Lowri Griffiths, Bowel Cancer UK

Beverly Luchmun, R&D Division at Welsh Government (BL)

Derin Adebisi, Royal College of Physicians

Rubina Ahmed, Stroke Association Wales (RA)

Dr Chris George, Swansea University (CG)

Angie Constable, British Liver Trust in Wales (AC)

Martin Fidler-Jones, Tenovus Cancer Care

Tim Banks, Tenovus Cancer Care

Gemma Roberts, CRUK

Jonathan Roden, BHF Scotland

Craig Lawton, BMA Cymru

Rachel Adams, Department of Biomedical Sciences at Cardiff Metropolitan University (RAd)

Matthew O'Grady, Stroke Association Wales

1. Chair's welcome and introduction, followed by a review of the last meeting's minutes and actions

Dai Lloyd welcomes everybody to the meeting and states that he's standing in as chair in AB's absence. DL welcomes Emma Henwood to share some news.

EH states that this zoom meeting is being recorded to help with taking minutes and this recording will not be published. EH announces that she is leaving the BHF and a new secretary needs to be elected. She puts forward Bethan Edwards, policy officer at BHF and asks members to voice any issues with BHF continuing the secretariat for the CPG.

BE introduces herself and expresses interest in taking over the secretariat if there are no problems with this.

DL congratulates EH on her new role and confirms with members whether they are happy with BE taking over as secretariat. Upon approval from members, DL confirms BE as the new secretary. DL introduces the first item on the agenda as an overview of the major themes from the inquiry responses.

2. Overview of the major themes from the written responses to the inquiry ***Bethan Edwards, Policy Officer, BHF Cymru***

BE confirms that 15 responses have been received so far and summarise the major themes emerging from the written responses:

- The implementation of the Reid Review recommendations and for Research and Innovation Wales to be formed to deliver these. There were also calls to clarify Welsh Government's (WG) position on these.
- The importance of increasing quality research (QR) funding.
- Uncertainty with regards to the post-Brexit landscape, in terms of funding and attracting and retaining research expertise. There was specific mention of the proposed Shared Prosperity Fund and importance of ensuring devolved representation and The Welsh Research in London Office.
- WG funding of medical research is lagging behind other UK nations which risks conveying a lack of commitment to research. The importance of having one overall brand of R&I in Wales was mentioned.
- Increased collaboration and the fact that WG need to be leading on this. The types of collaboration discussed include between academia and healthcare, partnerships within Wales, between Wales and the rest of the UK, and ensuring a relationship with the EU post-Brexit.
- Career prospects of researchers was discussed and the importance of ensuring stable career pathways - project-based nature of researchers was mentioned and the need to embrace research alongside practice-based roles. Sêr Cymru scheme was also highlighted.
- Protected research time and research within the NHS was brought to light. Clinical pressure was discussed as an obstacle for this and the importance of a wider cultural shift to ensure research is embedded within healthcare.
- Involving patients is vital but ensuring representation and diversity was noted as challenging.
- The importance of securing policy impact of research and ensuring outcomes of clinical trials are translated to practical changes was agreed.

BE finishes overview and asks anyone to get in touch if certain points haven't been covered or they feel haven't been translated correctly.

DL thanks BE for the summary of themes and repeats a welcome for those who had recently joined the meeting. DL gives overview of meeting ahead and introduces Andy Glyde to give his presentation.

3. Commencement of evidence from charities

CRUK Wales

Andy Glyde, Public Affairs Manager

AG thanks the CPG for the opportunity to speak and states that challenges have become even more relevant due to the ongoing pandemic.

Background

CRUK is the largest independent funder of medical researchers in the world. In Wales, CRUK funded £4 million last year.

Charity research is an important part of medical research as it's often higher risk discovery science which can be less attractive for external funding. But it's often this high-risk research which leads to clinical trials for life saving treatments.

Impact

In Wales specifically, CRUK funded clinical trials in Cardiff University at the Centre for Charles' Research. An Experimental Cancer Medicine Centre (ECMC) in Cardiff was also funded, which is part of a network of 18 centres across the UK. CRUK also funded a senior research nurse in Wales and co-funded 13 research nurses across Wales.

Researchers in Wales continue to play a big role in clinical trials in prostate and lung cancer in particular.

Medical Research Environment

In 2018, CRUK published the Bench to Bedside report which looked at the medical research environment in Wales. AG notes how the overview given by BE at the start is very similar to this report and proves that all members are saying the same things.

But the critical thing to get across is that Wales in theory, is set up for medical research in terms of its size, population, our health systems and our universities. However, it's not happening as well as it should be and if we take a look at one metric, the amount of research funding that Wales brings in, this is nowhere near as high as it should be.

Funding is preventing Wales reaching top levels and QR funding is the gateway to improving many other challenges currently faced in Wales.

It's also worth mentioning the Cancer Research Strategy for Wales which is being written, which the Cancer Implementation Group and Cancer Delivery Plan both set out to develop. A lot of the content will focus on wider issues which affect other areas of medical research too. What's important about this work is that it's included cooperation from WG, NHS, research community, third sector and industry.

Wales has a unique infrastructure - CUBRIC at Cardiff University & SAIL data bank at Swansea University. The critical element is how we bring these things together and make the most out of them as a country and produce world-leading research.

Brexit

It's not just the loss of funding that's the issue but making sure we're still able to collaborate with competitive global research.

The CRUK Grand challenge involves teams that deal with bigger issues and teams work together across the world. But none of the short-listed teams across two rounds of this funding scheme have ever involved Welsh researchers. This is something we should rectify.

Covid-19

Covid-19 will change the face of research. Laboratories have had to close and researchers have had to work from home, meaning many experiments have been delayed and progress has potentially be lost. Equally clinical trials have had to be cancelled and we know that in May, recruitment for clinical trials was down 98% compared to previously. This has a massive impact on patients too, as clinical trials often offer hope to patients who don't have access to as many treatments.

Staff/researchers with clinical background have been redeployed. Across the UK, the AMRC have estimated that 126,000 patients were unable to access charity-funded clinical trials over the last few months.

Trials have been able to continue but just in different ways. Those involved in research have tried their best to use innovating ways to make sure trials have continued.

We know that trials are starting to recover, however frameworks and guidelines in light of the pandemic mean that Covid-19 trials are being prioritised over non-Covid trials. We need to ensure that our progress is not lost.

There will be cuts and redundancies for researchers, particularly for early career researchers. This may well lead to a loss of an entire generation of researchers.

Impact on charities

At least 25% of CRUK income has been lost due to closing shops and missing out on fundraising events. This has led to difficult decisions being made and already we know that £44 million of our research budget has been cut this year - this may be forced to increase that to £150 million. Our spring funding round has had to be paused until the Autumn. In the long term, there's going to be less money and more applicants.

Solutions

There are solutions there, but we're talking about significant sums of money which WG doesn't have access to. WG does have an essential role to play in advocating for Welsh research to UK government.

There have been announcements regarding supporting universities, and we've had the new R&D Roadmap, but the money coming through to Wales through the Barnett formula needs to be prioritised.

CRUK, AMRC, BHF have been calling for a Life Sciences Partnership Fund which aims to mitigate some of the lost charity funding.

Moving forward

How do we create Covid-19 free sites to give people the confidence to go back to hospitals when they need to and to protect staff?

If there is to be a second wave, how can we learn from this experience and mitigate unnecessary damage to research and clinical trials? How can we use innovations from the first wave?

DL thanks AG for his presentation and introduces AF to give his presentation.

BHF Cymru

Adam Fletcher, Head of BHF Cymru

Overview of BHF in terms of medical research

BHF fund new research across a whole breadth of heart and circulatory diseases. A whole spectrum of careers are funded - early career researchers, PHD students, professors etc. The aim is to fund higher-risk research to better prevent, diagnose, treat and cure heart and circulatory conditions, which otherwise might not be funded. Some of the research that we fund is often picked up commercially after the risk has paid off.

Overview of our funding

BHF invest almost £500 million in medical research across the UK, but Wales only receives £3.7 million of this - 12 out of over 1000 projects are led by researchers in Wales. Scotland in comparison are receiving around £64 million and are leading 134 projects.

All BHF research is concentrated in two universities - Swansea and Cardiff University. There are lots of researchers across Wales who are probably not able to access BHF funding and who could be answering questions we've not been able to so far. BHF want to be able to reach them.

One of the reasons that so little research flows through Wales is the fact that we don't have a Centre for Research Excellence Centre or Accelerator Centres in Wales, which are key parts of the research infrastructure in the UK. There are two benefits of these centres, firstly they get a large investment up front, but they are also in a position to leverage more money over time. We need to build up a critical mass at one or more of our universities to be able to attract expertise and attract external investment.

Impact of Covid-19

We estimate that rather than investing £100 million into new research next year, we'll be investing £50 million. This means those who're currently funded by BHF may not be able to continue life-saving research. We want to try and continue funding a range of different areas - some PHD studentships, some smaller projects and some larger.

The research funding for Wales is likely to decline even further following Covid-19 and Welsh Government need to be advocating for medical research in Wales.

Positives

HCRW have recognised that there's a mismatch between the burden of heart and circulatory disease and the level of funding that gets directed to this condition. They've established a National Cardiovascular Research Network (NCRN) led by Professor Chris George. It involves 4 different Welsh universities, NHS Wales, BHF and Life Sciences Hub. Its receiving £250,000 for the first three years but this will hopefully attract additional funding from external investors and help build that critical mass.

BHF is funding data science more strategically in Wales, which is a strength here at Swansea University with the SAIL infrastructure.

The BHF Big Beat Challenge was also brought to light, where up to £30 million is provided to global teams for major projects. One of the applications involves a Professor at Swansea Universities to develop a hybrid heart. We need to see more support like this for Welsh researchers and elevate them to a higher level.

DL thanks AF for comprehensive slides and opens the floor to questions.

EH adds that it would be useful for each member to introduce themselves and the organisation they are representing.

4. Introductions

All those present at the meeting introduced themselves and are listed at the top of this document. Those who brought to light specific comments are mentioned below.

Lowri Griffiths, Bowel Cancer UK in Wales - we fund small amounts of research but none in Wales. Covid-19 has brought financial difficulties and our research portfolio is at risk.

Rubina Ahmed, Stroke Association in Wales. Only one funded PHD student in Wales which is surprising considering there's a centre for excellence in ophthalmology at Cardiff. There's clearly centres for excellence in specific areas in Wales, but it's about increasing capacity and collaboration to make the most out of these.

Louis Mertens, Royal College of Psychiatrists Wales. Represent sports psychiatrists including research psychiatrists and we are keen to increase the number of sports psychiatrists to be conduct more research as part of their clinical activities. In particular we wish to make the case for more clinical academic psychiatrist training posts in Wales.

Ann Tate, Chief Executive of Cancer Research Wales. We are estimating that our income will be cut by 44% this year due to Covid and we've had to furlough half our staff. We're funding £2 million a year of cancer research in Wales but we need to be evaluating where we can have the most impact with limited resources.

DL thanks everyone for their introductions and welcomes any additional questions or comments.

5. Questions and discussion including input from other charities

Rachel Adams - One of the mechanisms used by the UK government to support universities is the University Research Support Package. One of the metrics that will be used to determine who can access the funding is how much non-public funding universities are getting and this may well end up disproportionately affecting universities in Wales due to the smaller amount of charity funding in Wales. Is WG thinking about the effect this could have on the support the UK government's is providing for universities?

DL invites **Beverly Luchmun** to make a comment; BL states that there is no view to share on this today but notes that this is of course on WGs radar and she intends to take this back to senior colleagues.

DL notes that this could perhaps form the basis of a recommendation in the CPG final report.

Christopher George - enquires about the future direction of funding from both charities in light of Covid-19. CG brings attention to the fact that charities historically invest more in centres of excellence, none of which are in Wales, and questions whether the limited

amount of funding available after cuts will be redirected to these existing centres at the expense of developing new ventures.

AG states that this is still being worked through. Ultimately however, AG notes that CRUK want to fund the best research no matter where this is based and that they are keen to support cross-party ventures like this one to encourage a more collaborative and fruitful medical research environment and enable world-leading research.

DL questions what it takes to have a centre for research excellence in Wales.

According to AF, it's about achieving a critical mass in terms of people and expertise, but also about offering something unique. For instance, the new NCRN brings in CUBRIC. Using this infrastructure is key and what Welsh universities need to be doing is focusing on fewer projects rather spreading themselves thinly across a whole range of projects. In terms of answering CG's question, BHF still don't know the specifics on how funding is going to be directed after Covid-10.

AG follows on from AF's point and notes that it's not how Welsh universities need to be better than the Golden Triangle, but how Welsh universities collaborate and contribute to bigger, global partnerships by using their unique infrastructure.

Lee Campbell notes the importance of collaboration and a future research strategy. He explains that there are common underlying themes within the work of cancer, heart disease, stroke, dementia etc. and cross-cutting work needs to be identified so collaborative partnerships can be made.

LM brings attention to the unique expertise in Wales re: neuropsychiatry, neuro-psychiatric genetics and genomics. With Brexit however, this area is very much in danger in terms of attracting this talent and expertise. The fact that research contracts are often short term and unstable also jeopardises this, which adds to the value of increasing the number of academic training posts for clinicians in Wales.

DL agrees with this point and notes the possibility of including this as a recommendation in the CPG report. DL intends to speak to AB about this.

Angie Constable raised the point that it is important to have things based in Wales itself as it helps to shape the services and the treatment and care that patients receive.

RA - We're primarily focused on service delivery at Stroke Association, but we have tried to partner with HCRW and we do have ring-fenced funding for Wales. However, we've never been able to attract a fundable application. It would be useful to know where it would be most valuable to direct our funding, and what type of research Wales is doing that we could look to fund.

Mathew O'Grady raises the Stroke Hub Wales which has been a successful infrastructure project. But this is linked with WG Delivery Plans as part of the funding for this came from the Stroke Implementation Group. With uncertainty over the future of delivery plans and now Covid, there's uncertainty over funding linked to these projects too.

6. Any other business

DL asks if any members have any additional points to raise.

BE raises the possibility of asking members to submit renewed written evidence in light of Covid-19, with a maximum submission of two A4 sides.

DL agrees with this stating other committees and groups have responded in a similar manner.

EH mentions that some universities are yet to provide an institutional response to the written inquiry and questions whether we should be sending a reminder to Welsh universities, particularly as the next evidence session is reserved for hearing from HEIs.

DL agrees that a reminder would be beneficial.

CG explains that Swansea University has been between Pro-Vice Chancellors for Research and that he will follow this up with the new person appointed.

DL calls for any final business and invites EH to say a final few words.

EH thanks everyone for their collaboration and engagement and hopes that under BE and AF's stewardship that the inquiry report for the CPG will be delivered and that we can make a difference in this space.

DL reiterates thanks on behalf of the CPG for EH's support and the meeting is closed at 3.15