

Cross Party Group on Medical Research
Third meeting of 2019

Industry

10 July 2019
12-1.30pm
Conference Room A, Ty Hywel

Minutes

In attendance

Angela Burns AM, Chairing (AB)
Dr Dai Lloyd AM, (DL) (arrived at 12.30pm)

Presenting:

Catrin Middleton, Cardiff and Vale University Health Board (CM)
Ali Hansford, ABPI (AH)
Gwyn Tudor, Life Sciences Hub (GT)

Mark Major, Caroline Jones AM's Office
Mike Bryan, Angela Burns AM's Office
Mark Briggs, Welsh Blood Service (MB)
Lowri Griffiths, Royal College of Physicians (LG)
Dr Gareth Llewellyn, Royal College of Physicians
Chris Thomas, Cardiff University Biobank
Joe Ferris, ABPI (JF)
Gethin Jones, Royal College of Paediatrics and Child Health
Andy Glyde, CRUK (AG)
Rhian Thomas-Turner, Noah's Ark Children's Hospital for Wales (RTT)
Nigel Rees, Welsh Ambulance Service
Sue Bale, Aneurin Bevan UHB - Medical Directors Office (SB)
Alexander Smith, Stroke Association Postgraduate Fellow
Chris George, BHF Researcher (CG)
Louis Mertens, Royal College of Psychiatrists
Delyth Morgan, Head of Research Programme Development, Welsh Government
Josh James, Diabetes UK
Ryland Doyle, Mike Hedges AM's office
Tom Cosgrove, BHF Intern
Tom Rhydderch, BHF Intern
Emma Henwood, BHF Cymru (EH)

1. Introduction, welcome and review of minutes

Angela Burns welcomed everyone and everyone introduced themselves. She then asked to review the minutes. The minutes are agreed. AB then asked Lowri and Dr Llewellyn to give a quick overview of the report the Royal College of Physicians in Wales launched that day. LG had brought the report

2. Catrin Middleton, Cardiff and Vale University Health Board

A United Approach to Genomics in Wales

- Catrin Middleton presented an overview of Genomics for Precision Medicine Strategy, formed by the Welsh Government in 2017 and the implementation of the programme to advance precision medicine using genomics.
- Genomics Partnership Wales was formed to deliver the strategy, setting a precedent for using genomics for the advancement of healthcare
- Five core themes of the strategy: Co-production, Clinical and laboratory services, Research and innovation, Workforce and Strategic Partners.
- Finance has been put behind it to develop the service and to map genomes. It is an All-Wales service which serves each Health Board with genetic testing.
- Statement has been drafted pulled together which is to harness the potential of genomics to improve the health of the people of Wales.
- Workforce needs to be looked at - at present one element of a patient's genome might be tested but in the future, a GP might send a patient to have their whole genome tested which will require development.
- Money for the project is ring-fenced and can be moved where it needs to be to best deliver for the project.
- The co-production theme involves a three-tiered approach to working public whereby two members of patients have been appointed to sit on the Governance board. This ensures top down patient involvement.
- The members of the Patient and Public Standing Board all have links to genetic disease and is almost representative of the entire country. The Board are consulting on consent models and how to improve patient experience throughout genetic testing.

Questions

SB - It may be worth producing a central resource which sets out the payback for the patient on the website.

CM - I'll take a look into it.

CG - Has there been integration with England and the 100,000 genomes project?

CM - A research perspective from the UK Government is to work together across the devolved nations. Wales contributed 400 patients to the 100,000 Genome Project and we have received all of the test results back. There has been an extension by the UK Government to sequence 5 million genomes. They wanted Wales to work with them to develop a national genomic sequence. With the 100,000 Genome Project, we were promised that the 400 participants' data would be returned to us to match up to the SAIL data bank but this commitment was broken.

MB - Patient panel could be useful to his work at the Welsh Blood Service as the issue is people could be becoming personally genetically modified and the service can work together to ensure these issues are debated with patients, and they are

looking for representatives who can help to shape the strategy. How can AMs help get Wales a seat at the table in the discussions with NHS England?

AB - what are the reasons why cooperation is lacking?

MB - At senior level they do think it is happening, but Wales is seen as being too small to be relevant. We want to learn from them (NHS England).

CM - England have implemented a strategy to sequence the genome of every child with cancer. Wales looking to do this on evidence based cases because we don't have the capacity, money or data to do this ourselves. We do not need to follow England but a discussion needs to happen.

AB - This group can write to the Secretary of State for Health to put these issues forward. We will wait until the new Prime Minister has decided his new cabinet.

ACTION - EH to draft a letter when the new Secretary of State is in position.

3. Ali Hansford, The Association of the British Pharmaceutical Industry

The view from the pharmaceutical industry on an overview of commercial clinical research, skills needs and gaps and the impact of Brexit

- ABPI represents 80% of brand medicines used by the NHS.
- £34.8bn was spent on research and development in the UK in 2017.
- The largest expenditure by a single sector was the pharmaceutical industry (£4bn / 18%).
- In 2018, 900 clinical trials were opened and started both academically and commercially. The UK's trials made up 28% of trials across the EU that year.
- Since the referendum in 2016, there has been a slight fluctuation in the number of trials being carried out in the UK, however, the proportion of trials compared to the EU as remained steady. There is anecdotal evidence of trials being pulled due to Brexit.
- The UK Government's industrial strategy set an ambition of UK clinical trials competing globally. These goals involved increasing the number of trials by over 50% over five years. There is a drive to increase the number of novel technologies being used.
- ABPI have four main Brexit Policies; securing the ability to trade and move medicines across borders; securing regulatory cooperation; an immigration system that allows companies to employ the best talent from around the world and the EU; and securing predictable funding and collaboration for research.
- ABPI and NIHR recently produced a report on complex innovative design trials. They pulled together and put out best practice ideas on how to deliver in the UK.
- The NIHR are creating five centres which specialise in late phase clinical research. They will use standardised measures to specialise in rapidly recruiting many patients.
- Skills and workforce - ABPI developed skills strategy and every 2 years a skills gap survey is undertaken. January 2019 showed there was a genomics and AI

skills gap. Pathologists and Clinical Pharmacologists gaps are often identified by this survey.

Questions

MB - In terms of attracting trials to the UK, the statistics often don't reflect anecdotal comments regarding the difficulty many report in setting up trials. Setting up trials in the UK is hard and we are in global competition.

AB - is Brexit is the main reason for the difficulty in setting up trials?

MB - not necessarily.

AH - The Clinical Research Working Group (CRWG) and the Office for Life Sciences are working to produce content on what the UK offer is to help win the international contracts for trials.

MB - Are the five centres England or UK based?

AH - Locations are yet to be decided and NIHR has stated they'll be but they'll be smaller than first thought with two or three staff per centre.

LG, GL and DL left at 13.06

RTT - How do we ensure that children's trials are not unfairly disadvantaged due to Brexit as the market around rare diseases and research into childhood disease often involves smaller trials?

AH - part of ABPI strategy, very aware and trying to ensure this is not missed

AG - Wales isn't competing as well as the other UK nations. Are we doing as well as we could be?

JF - Our feeling from members is that it is getting harder to sell the UK, especially outside Golden Triangle (London, Oxford, and Cambridge). LS Hub have big role to play in Wales.

4. Gwyn Tudor, Life Sciences Hub

The research and development landscape in Wales for medical technology, diagnostics and digital health care solution.

- Answered the previous question. Wales does very well on life sciences, but it is generally accepted that Wales is not doing as well as it could in terms of attracting UK funding.
- Life Science sector is rich and varied place. 370 companies and 11,000 staff.

- LSH are being challenged to support healthy ageing - often the companies doing a lot of work in this field are more diverse than just life science companies.
- There are Big Data opportunities, alongside companies looking at precision medicine there are also telecoms companies looking at how we keep people connected.
- The sector is becoming more complicated and a variety of solutions are required. Other healthcare needs being met through drug discovery, basic translational research and invention - not just formal research. These then need to go through formal trials.
- Health Technology Assessments are driving a higher standard of evidence as to whether Wales needs the product, is good value for money and is safe.
- Identify the priority needs within the healthcare sector and then identifying partners who can ensure these needs are met.
- The Accelerate Programme will allow industry partners to collaborate with academic institutions to undergo Health research.
- LSH bridges the gap between health service and industry.

Questions

MB - Where does research become innovation, become service improvement? We need to harness the necessary players to make something happen - no one organisation can make everything happens. LSH is critical to feed into the system, but then we need to open up the NHS to engage with external partners and make a slick process. Long term strategic plan, doesn't happen overnight.

AB - Where is the line between research and innovation?

MB - Innovation is taking what we already know and applying it in a new way. Google search algorithm can also be used to understand how proteins and enzymes work.

GT - Innovation is the successful implementation of a new idea. Lots of organisations being asked to "do" innovation, but it doesn't become innovation until it is successful. People in the NHS need to have the space and time to work on innovation and research.

AB - Lots of talk today has centred on the NHS rather than academic institutions reluctance of universities - don't want to let the IP go due to

JF - retaining IP has become a big thing for NHS - how do all the partners get what they need

SB - Need to have agreements early in place.

JF - WG working on getting something for the NHS that they can use for their agreements and retaining IP.

NR - A real need for a shared document across the NHS. Misunderstanding of IP in the core NHS contract

GT - should have a competitive advantage due to our University Health Board structure

JF - Manchester area/region have managed to take devolution and do this kind of work very quickly and very well.

SB - Twice as much money going into research in Greater Manchester than Wales.

5. Inquiry

- EH presented the response from Kirsty Williams in reply to the letter from the Group which stated that with regards to the Reid Review's recommendations 2 and 3, the Government has made it clear that they can only be achieved using funds secured alongside UK Government's replacements for EU structural funds.
- Inquiry paper which came out with the papers for this meeting: some organisations who could not be here today have fed-back
- Invite you to feedback with regards to the themes and questions we want to ask as part of the written evidence.

AB closed the meeting at 13.30