Cross Party Group on Medical Research
Second meeting of 2019

Research in healthcare settings

8 May 2019
12 – 1.30pm
Conference Room C, Ty Hywel

Minutes

In attendance

Dr Dai Lloyd AM, Chairing (DL)
Mike Hedges AM (MH)

Presenting:
Mark Briggs, Welsh Blood Service (MB)
Mandy Edwards, Cancer Research UK Senior Nurse for Wales (ME)
James Coulson, Cardiff University (JC)

Emma Henwood, BHF Cymru (EH)
Ryland Doyle, Mike Hedges' office
Joe Ferris, ABPI
Lee Campbell, Cancer Research Wales (LC)
Andy Glyde, CRUK
Gemma Roberts, CRUK
Mike Bryan, Angela Burns AM's Office
Josh James, Diabetes UK
Kate Shires, Cardiff University Biobank
Chris Thomas, Cardiff University Biobank
Martin Fidler-Jones, Tenovus
Lynne Davies, CRUK
Sarah Shankland, Cardiff UHB Research Network
Huw Owen, Alzheimer's Cymru
Ed Bridges, Cardiff University
Mark Major, Caroline Jones AM's Office

1. Minutes
Dr Dai Lloyd AM asked if minutes were accurate
Emma Henwood confirmed that as part of the actions from the minutes she had written to the Health, Education and Economy secretaries to ask if the Government could outline their work to date on the actions of the Reid Review and that a response was expected in due course. She also circulated the terms of reference of the group which was an action from the previous meeting.

2. Mark Briggs, Welsh Blood Service
Advances in science and medicine and their use in the NHS

- Mark Briggs presented on the outputs of research in his field, leaps in innovation and technology alongside therapeutic genomic research.
- Mark made reference to the Health Minister's recent statement on integrated diagnostics with technology and care.
- These new therapies are expensive, but present a great opportunity for the NHS to move forward if technologies are embedded into other innovations, efficiencies and opportunities.
- Recognised at UK level and devolved nation level that this must be a part of the future developments of healthcare.
- FDA in America estimates that there will be 25-40 of these new therapies in the next year with 10-20 every year after that.
- In Wales, there are business cases and costed implementation plans to see if these can be taken forward and help to educate the public and cost analysis with help
- Currently there is no governance and experience, no infrastructure in this area in the NHS.
- Proposals to see if we can map out what the new clinical pathways will be and testing real world challenges such as digitised container ships and compromised samples
- UK Government ATTC programme has put up funding to understand what some of the challenges might be in this space and to inform an all- Wales strategy to ensure NHS can deal with this.
- What is the big ask from WG and how can we support the transformation of the NHS.

Questions:
Josh James – Is there any way we can use these developments to change the way we deliver services such as preventative approaches?
MB – Yes, but there are other ethnical and societal issues such as if you know you might get a disease what might that do to your car insurance etc.? Or potentially changing the genome of your future family.

Dr Lloyd suggested a short break for the lunch which had been delivered during the first presentation.

3. Mandy Edwards, Cancer Research UK Senior Nurse for Wales
Running research projects in the NHS

- Nursing view of running research projects in the NHS
- CRUK 12 co-funded with Government research nurses. The role is to actively promote the research the nurses do, acting as experts and leaders within the clinical trial field.
- Health boards can have difficulty with garnering clinicians to buy into research, and to become principle investigators (PIs). Chief investigators (CIs) are responsible for national programmes and bringing in money to research
- Treatments have become more complex which increases the workload and decreases the number of patients who are eligible for trials as treatments become more focused on individual cases

- Length of time to identifying a study to opening it can mean projects don't open – due to staffing changes or infrastructure capacity and organisational and administration processes. It also means that studies have to be prioritised due to capacity
- Tests required in a certain time frame and without capacity means that patients often miss the window to participate in the study
- Lack of funding in universities which has a knock-on effect on NHS studies
- Recommended that PIs could come from a wider number of professions within the NHS
- Time in workplans must be allocated to research

MB – Need to break the cycle because research centres deliver better treatment to patients. Commercial trials will also enable the research to be paid for and so is more cost effective
DL – Patients getting involved in studies get better treatment
LC – University research gets stuck not getting into clinical trials so clinicians hold the key
ME – Victim of own success because recruitment can drop because a lot of patients require follow up. Procedural issues such as archiving 15 years' worth of data are often required.
MH – Why can you not digitise the documents?
ME – Often this is a requirement from a project and there are specific rules for archiving
MB – Part of the ATTC work is to look at issues such as that archiving problem, to come up with what is required, what's custom and practice and what innovation can be done in this field.

4. James Coulson, Cardiff University

Clinical Toxicology in a medical setting

- James gave an overview of how he came to be speaking, via a call from the RCP looking for clinicians who were PIs and he thanked Mandy for her introduction into PIs and CIs and the issues they faced.
- Part of the role is innovation and engagement, with UK and Welsh Government, academia, industry
- Pharmacology is the response to the drug – how much you take and the concentration in the blood, what's the effect
- Efficacy, what will be the outcome and will it help someone live better – toxicology science of safety
- Not many clinical pharmacologists in Wales or in the UK or the world so how do we ensure what the pharmacologically active dose of drug is to make sure it's safe from the benchside.
- Efficacy to harm ratio: by monitoring the drug in action –help clinical colleagues to ensure they get the best output
- How do we know we're achieving the outcome we believe should be the case
- Helping individual health boards in Wales optimise their therapeutic decision making
- Current health technology processes are fit for the new technologies

- 16 clinical toxicologists in the UK, 5 practising in Wales, so we are in a privileged position
- Working with industry medical research council, and there is a large study into optimising anti-hypertensive medicines at the moment
- No time for research in the university programme anymore – 1/12th of time to devote to clinical research – CI role key enablers, really need to free up that time for clinicians
- Realignment of resources? All working towards the same aims but it isn't easy for the NHS staff to access.

MH left the room

MB – Is most of the work on small molecules?
JC – Moving towards genomics now too. Most of the immuno-therapy work he has been done outside of Wales
Keen to be involved in the translation of research into therapies
LC – Pharmacological genomics hasn't made its way into the mainline clinical decision making processes – what changes are needed?
JC – Gene therapy hasn't gone as far as it was thought 15 years ago
Personalised medicine and private companies – information we get isn't that helpful
Metabolism of medicines genes have a big part to play they're not going to be a panacea. Genetic markers – rare life threatening adverse effects of drugs – tests for these markers. How do we harness these and ensure we take the best for patients?

5. Update on CPG work – inquiry

- Writing to Ministers on the Reid Review – add value, add to policy making signatories AMs to this group
- More discussion offline about the inquiry
- In our three meetings to date, we have heard from "Classic" research in universities, social research, and now today healthcare settings – which is as a result of the subgroup we heard from at the last meeting
- Don't want to recreate either the Reid Review or CRUK's Bench to Bedside
- Do we want to take evidence from Universities or should we be hearing from more contributors
- We haven't heard from any patients or industry yet
- Get a plan signed off by the signatory AMs to the group

MB – industry perspective would be helpful. Genomics – can't own that research so would industry be happy to invest in this even though they can't benefit from it economically
JF – Life Sciences Hub, and get industry to the next meeting. Don't have the best track record of delivering on research at the commercial level and have lost our place globally.

Dai Lloyd closed the meeting at 12.21.