

Cross Party Group on Medical Research
Fourth meeting of 2019

First Inquiry Session: Patient and public involvement

19 November 2019
12-1.30pm
Conference Room A, Ty Hywel

Minutes

Apologies

Martin Fidler-Jones, Tenovus
Gwyneth Sweatman, Marie Curie
Christopher Thomas
Christopher Fegan
Sue Bale
Valerie O'Donnell, Cardiff University
Michaela John, Genomics Partnership Wales
Joshua James, Diabetes UK Cymru
Katie Chapelle, Stroke Association Cymru
Matt O'Grady, Stroke Association Cymru
Gethin Matthews-Jones, Royal College of Paediatrics
Nicholas Webb, Royal College of General Practitioners
Gareth Llewellyn, Royal College of Physicians

In attendance

Angela Burns AM, Charing (AB)
Dr Dai Lloyd AM, (DL) (left at 12.30pm)

Presenting:

Alex Newberry, Health and Care Research Wales (AN)
Astrid Burrell, patient representative (A)
Radha Nair-Roberts, patient representative (RN)

Mike Bryan, Angela Burns AM's Office
Emma Henwood, BHF Cymru (EH)
Adam Fletcher, BHF Cymru (AF)
Bethan Edwards, BFH Cymru
Andy Glyde, CRUK
Louis Mertens, Royal College of Psychiatrists
Rhian Thomas-Turner, Noah's Ark Children's Hospital for Wales (RTT)
Alexander Smith, Stroke Association Postgraduate Fellow
Ryland Doyle, Mike Hedges AM's office
Sarah Williamson, Royal College of Physicians
Mathew Norman, British Lung Foundation Cymru
Carys Thomas, Health and Care Research Wales
Callum Hughes, NHS Confederation
Lee Campbell, Cancer Research Wales (LC)
Ann Tate, Cancer Research Wales
Tegid Roberts, patient representative
Kirsty Foxhay, Intern in Dai Lloyd's office (left at 12.30pm)

1. Introduction, welcome and review of minutes

Angela Burns welcomed everyone, and everyone introduced themselves. She then reviewed the minutes. The minutes are agreed. AB reminded attendees that the inquiry process has been launched and there has been a call for evidence.

AB also noted that she has been in discussion with those who are involved in pharmaceutical analysis, and questionnaires should be sent to them. She then reminds attendees to consider any organisations which may want to participate. Emma Henwood will circulate where the inquiry has already been sent already.

EH update from last meeting. Dr Middleton from the Genomics Partnership Wales, said in the last meeting that there were difficulties between the genome project between England and Wales. In our actions we agreed to write to the Secretary of State for Health to offer our support. However, Dr Middleton asked this to be put on hold on as there was sensitive work ongoing. This action is on hold.

2. AGM

The AGM report had been circulated and includes a note of the meetings held, the main topics of conversation and our financial statement. AB asks if anyone would like to add anything, everyone was happy with the content.

Election of chairs and secretary of CPG is discussed. Dai Lloyd and Angela Burns nominated as co-chairs and Emma Henwood nominated as Secretary.

AB expressed her gratitude to EH as Secretariat.

3. Presentation from Alex Newberry, Health and Care Research Wales, followed by perspectives from Astrid Burrell and Radha Nair

AB introduced Alex Newberry to discuss public involvement in medical research, Astrid Burrell who was a carer for her husband who had Huntington's Disease, and Radha Nair to talk about what it is like living with a neurological condition. RN confirmed she was a medical researcher before being diagnosed with her condition and can therefore provide both perspectives.

- AN provided an overview of Health and Care Research Wales (HCRW): virtual, national health and care research organisation, the delivery arm and external brand of WG Health and Social Services Research & Development Team.
- Key aims: stimulate research excellence, build capacity and capability and support research delivery. Done through developing policies and strategies, running annual funding calls & running research grants. Annual allocations to NHS organisation are also provided for research programmes, as well as buying into English funding programmes so Wales-based researchers can access.
- The importance of public involvement (PI) in research. The public can interact with research through three domains: public engagement as people are aware that research is happening, public participation, and sharing knowledge and experience throughout the research process itself.
- AN addressed why public involvement has become important in the last five years: makes research relevant; helps define what's acceptable to participants; supports ethics committees particularly on sensitive or controversial issues.
- Helps to ensure research is not jargon-filled and over-medicalised in a way in which the general public will not understand.

- Public Involvement Delivery Board includes members of the public, and multiple public members in funding panels. The public is also involved in the ethical review of research and there is a public involvement team dedicated to managing and helping members of the public who are part of the research community. The PI team also provide training to researchers on involving the public in their current research, and to the public on how to be engaged.
- AN noted the importance of ensuring that PI does not become tokenistic.
- The promotion and dissemination of the Public Involvement Standards have recently been published. After a meeting with the PI Board, a vision document which sketches out the next steps for PI will be created, and that this will be developed in a co-productive manner including both the public and researchers.

Astrid Burrell

- A's husband had Huntington's Disease for over thirty years. She discussed how living in a rural area made it difficult to find anyone who had experience with HD. A was then invited to a meeting in 2011 where patients and carers were asked to comment on a research application that a professor was submitting.
- The professor really listened and was willing to implement ideas. A was asked to join the HCRW Involving People team, to participate in other research projects. One was the Trident trial for brain cell replacement therapy in HD.
- A big part of her role is to ensure that when documentation is drafted that information is explained in clear language.
- The key to successful PPI is to respect and listen to each other. PPI is important that a researcher ensures that their work is appropriate and relevant to the needs of patients.
- A noted how it has given her a sense of purpose since she is no longer a carer and how it has boosted her self-esteem and self-worth. Intellectual stimulation.

Radhar Nair

- RN was a medical researcher working within the field of neurological conditions for most of her career. She worked on embryonic stem cells as part of treatment for Parkinson's and HD. RN then explained that in 2015, she woke up and progressive MS had paralysed half her body. She noted the mental health challenges she faced when she became disabled.
- RN noted the impact on the family of a person with a disability and discussed how many unpaid carers suffer from mental health issues too.
- Discussed her experience using NHS services for mental health, how beneficial the counselling was but she had to wait 6 months and the fact it only lasted 8 weeks long. She was prescribed many psychotropic drugs, but that they did not work for her and the side effects were unbearable.
- RN discussed alternatives to medication and social prescribing. She noted the importance of social activities for people with a disability.
- She was granted funding for two years to look at physical disability and mental health. Organised one event for people with a disability which included mindfulness, art therapy and music therapy. Attendees expressed a positive view on these types of events.
- RN spoke about WG and NHS response to this problem, which is running a pilot in two areas in Wales which is costing £1.3 million. The problem with using pilots is they take

too long to be evaluated and rolled out pilots also continue to exclude a large part of Wales.

- RN brought along a video to share with attendees but due to technological issues this couldn't be played. EH agreed to share the video via email.

4. Questions and discussion

AB expressed thanks to all the speakers and opened the floor to any questions.

RTT to AN - With regards to your PI Delivery Board, do you have any children with specific medical conditions sitting on this? Cancer, diabetes etc.

AN - Opportunities are open to everybody. The challenge with PI is that you want to be as inclusive as possible, but you also don't want to set expectations too high. You don't want people to come and want to get involved, but having no specific research projects for them to be involved in.

RTT - Asked how to ensure opportunities are open to children. Some of the research infrastructure groups like the Wales Cancer Research Centre primarily deals with adults; the Wales Cancer Research Strategy is silent when it comes to children, so how do you ensure that a child's perspective is considered, and their voices are represented?

AN - It's how we support the researchers to do that. One of the UK PI Standards for instance, is inclusive opportunities, which starts to drill down into what and who is your research relevant to and how do I get the most appropriate voices. It's a lot to do with culture change.

RTT - How does WG engender this culture change?

RN - Ethical implications of including children in a research project are massive. It should be done, but with a lot more ethical consideration.

AB - Surely the point being made is we are currently being unethical because we are not targeting children. AB mentioned *The Invisible Woman* showing medical trials are male dominated. What works for a man doesn't necessarily work for a woman. Similarly, very recently it's been uncovered that stroke symptoms for women can be different to men. We may be disenfranchising children by not including them.

RTT - Children aren't being given the choice and in coproduction of services you have to be over 16 to have a voice.

LC - Example from Scotland with stem cell donors. Younger people make better donors for bone marrow transplant for stem cells, so have reduced the age to 16. Younger donors are empowered; contributing to society; it changes their ethos.

AB - 16 year olds are allowed to be organ donors. Asked AN if there is general acknowledgment that there needs to be a sweep first across the genders to eliminate bias and then down to children?

AN - Difficult for WG because culture change is required. We should be supporting peer to peer culture change and trying to find ambassadors/advocates and get them to influence their colleagues.

LN - Culture is slowly changing in the cancer environment, where patient involvement includes involvement in trial design and deciding what primary and secondary end points

are important for the patient. What the clinician thinks is important and what the patient thinks is important might be different things.

A - Need to create an atmosphere where researchers want to involve patients. That's the role of those already involved in PPI so researchers see how useful it is. Certainly, all the ones I have worked with over the years do appreciate it.

RN - researchers I've worked with have been keen for this, particularly when it comes to reading documentation and checking the language that maybe divisive or too technical. What we can provide in terms of lived experience and just being outside of the research is extremely valuable.

A - The things that we review are not necessarily life-saving drug trials, that's only a minor part of the research. We can also be involved in lifestyle trials too.

RN - What matters to us is the capacity to function as human beings and be a part of society. It's about living life well with whatever illness you have and government should pay attention to this side as well as the medical side.

AB - Issue is all groups end up being marginalised, and society needs to involving people in discussions about their future and about their illnesses, conditions and sufferings they go through. We need to open our hearts and listen.

AF - BHF is funding a study at Cardiff University looking at how you can detect young people with congenital heart disease. The study involves the children but also their families and paediatric cardiologists that were involved in their care.

RTT - We do need to make sure the mechanisms are in place for the children to share their voices and not just the parents.

AN - I can take this back to the team.

A - Health and Care Wales Conference last year, we met a researcher who was looking at diabetes and worked a lot with children. It depends who comes to you.

RTT - Ensure mechanisms are there so not only people coming to researchers, but that they are going out to the children. How do we make the whole research infrastructure available to them? Wales-wide, not just individual cases.

AF - If we agree that Wales is falling behind, Sally Holland, the Children's Commissioner is the person to take to.

AB - Lynne, Dai and I sit on the health committee so we can also discuss this there.

AB left EH to wrap up the meeting as she had to leave for Plenary.

5. Any other business

None was recorded