



BRAIN

Repair & Intracranial Neurotherapeutics



Ymchwil Iechyd
a Gofal **Cymru**
Health and Care
Research **Wales**



Ariennir gan
Lywodraeth Cymru
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From the bench to the bedside: addressing the inequalities of public involvement in neuroscience research

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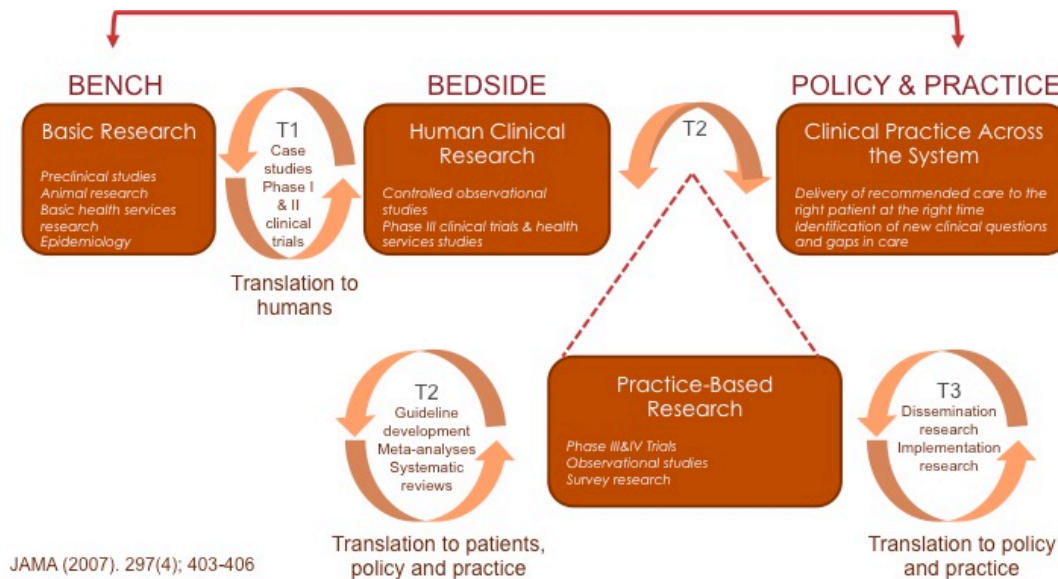
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Public Involvement in Neuroscience

- Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit established in 2015 to develop novel therapies for brain repair



Public Involvement in Neuroscience



- Developed a public involvement group called BRAIN Involve so research within BRAIN is designed and developed *with* people affected by the disease not *for* them
- Recruited 12 people affected by neurodegenerative diseases to join BRAIN Involve
- In 2016 we reviewed activity of the panel and found that 100% of panel use was by researchers working directly with people affected by neurodegenerative diseases – ‘Bedside’ research

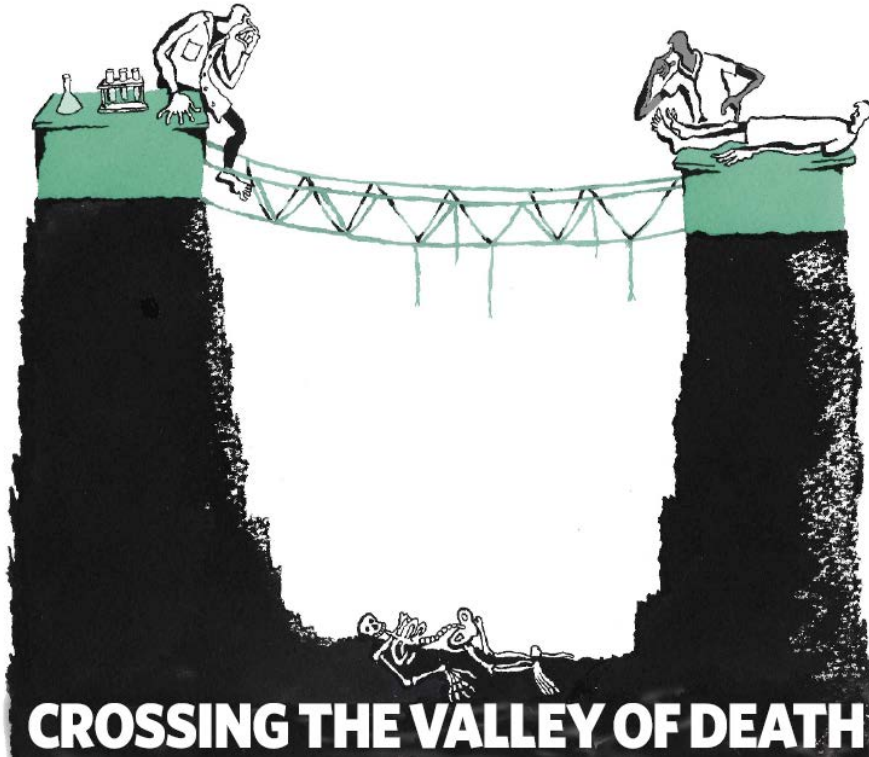
Why does this matter?

- Developing health research *with* people affected by a disease is often thought of as leading to research that is...
 - ... more relevant, more reliable and more likely to be used to improve health and social care services because it puts the person affected most by the issue at the *heart of the research* interests and outputs.
- Mission – to embed involvement within BRAIN
- Increasing requirement from funders
- Increased competition for smaller pots of funding
- Public money = public benefit

Why does this matter?

NEWS FEATURE TRANSLATIONAL RESEARCH

NATURE | Vol 453 | 12 June 2008



Success rates in
translational science
less than 1%

Methods

- Focus group – 03.03.2017
- N=9
 - Health professionals (clinicians, nurses, physiotherapist); lab based scientists; specialists in trial design; Manager of Involving People Network
- Two facilitators
- Three areas to explore:
 - 1 Do you believe that PPI is appropriate to all areas of research? Can you expand?
 - 2 How do you think you could use or benefit from PPI in your area of research?
 - 3 What information/understanding/training do you think a patient or member of the public needs, if any, to provide useful PPI?

Thematic analysis

153 codes generated



12 themes extracted



4 overarching meta-themes

Clarity

- Fear of the unknown

 - “it’s difficult to see how you do it”

 - “I hadn’t heard of before I got sent the information sheet”

- Managing expectations

 - “We have to know what’s being expected of us to be able to do it to be eligible for money that’s being provided and that’s we’re tied in knots”

 - “asking the funders exactly what it is they perceived the PPI to be”

 - “I wonder if anyone on the funding panel has ever tried to do PPI themselves”

- Committed

 - “we want to be doing this well, we want to be doing what you want us to do”

No questions asked

- Enhancing clinical research

“For me there’s no question on the patient end, on the clinical end. We need it, it’s important but we need to do it well...”

“spark new ideas of new projects that wouldn’t have happened unless they had organised that meeting which is not organised by scientist ”

“where PPI did work for me is actually... was the RFPPB grant... through the PPI they introduced me to social services in the Vale of Glamorgan... now I never would have heard of that without... ”

“ they see the world from a different angle ”

Challenging the field

- The expert voice
 - “if you’ve had to study your degree and get a PhD and do post-doc time to be able to write grants you cannot just take someone from the public and say, ‘okay, how would you write that?’ that’s never going to work ”
 - “the public know better than a group of people that have dedicated their life to it”
- Patients are distant memories in basic science
 - “quite far down the chain and what we’re actually looking for is to find an answer, if you don’t know what the answer is going to be it’s hard to say how it’s going to impact”
- Blue-sky thinking
 - “the technology that everybody is happy to use... all of that or most of that or lots of that comes from projects that would probably have been killed by the public; ‘this is a waste of money. We don’t understand that’ ...”
 - “I think they [public] cannot necessarily grasp what is the important of basic science that isn’t going to give a result three years from now but maybe twenty years from now because many of the things that people do now are based on research that is twenty years’ old”

Engage to involve

- Reversing the pipeline
 - “it’s reversing that pipeline that we would normally look at. It would be involvement, participation, engagement but actually what we should be doing from a basic research perspective is bringing the engagement forward to enable involvement”
 - “you need to engage before you’re involved”
- Duty of care
 - “the level of information of a general public and of patients is too low and second that scientists should than do something about it and try and raise it”
 - “informing the public is very important, even on relatively complex...even here”
 - “engagement is much more important than involvement and also raising the general knowledge of society”
- Expert voice
 - “getting them to help us with engagement... we do engagement and we have no idea what it is they want to know from our research”
 - “public perspective on how we actually communicate ”
 - “public involvement through education versus public patient involvement through collaboration and co-production”

Conclusions

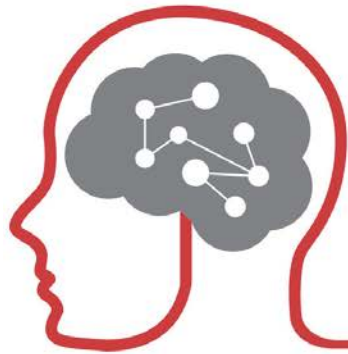
- Neuroscientists see a value and need for public involvement across the translational pipeline but they need clarity and support to design and implement involvement that will enhance research development in this field
- Healthwise Wales - In order to understand health of the next generation we need to look at current population
- Why not the same principle for involvement?
 - It may be premature to expect involvement in all stages of the pipeline without first investing in educating the national about the value and benefit of all types of research

With thanks

- Collaborators:
 - Professor Monica Busse, Barbara Moore, Peter Roberts, Dr Emma Lane, Sarah Evans

- Focus group attendees

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Questions?



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