Public and Patient Involvement in Health Research in Ireland?

REPORT

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Background

The Medical Research Charities Group (MRCG) is an umbrella group of medical research and patient support charities, which represents the joint interests of charities specialising in restoring health through medical research, diagnosis and treatment and, where possible, the prevention of disease. A core belief of the group is that today's health research is tomorrow’s healthcare.

The MRCG conference, held on 27th September 2016, was on the theme “Public and Patient Involvement in Health Research in Ireland.” The conference built on the work the MRCG have already done in this area and further promoted PPI to ensure that it becomes embedded in the research agenda setting process while also empowering patient groups in this area.

Left to right: Grace Cappock (MRCG) Michael Griffith (First Chairperson, MRCG & Co-Founder, Fighting Blindness) Philip Watt (Chairperson, MRCG & CEO, CF Ireland), Marie Downes (MRCG)
The event was chaired by Philip Watt, MRCG Chairperson and CEO of Cystic Fibrosis Ireland. “It’s heartening to see how much PPI has come on in recent years in Ireland,” Mr Watt told the attendees. “But it remains clear that we still lag far behind many other countries and a lot more work still has to be done.”

He continued: “While I was watching the Clinton-Trump debate, it reminded me of the State of the Union address that Obama delivered in January 2015, when he used his address to announce the Precision Medicine Initiative (PMI). Through advances in health research and health technology and policies that empower patients, the PMI is helping to create a new era of medicine in the US. It’s an era that is bringing together researchers, providers, funders and patients to develop new therapies that take into account the individual variability in genes, environment and lifestyle that many patients have.”

“We hope that through today’s conference, we can build on previous work by bodies such as the Health Research Board (HRB), IPPOS (The Irish Platform for Patient Organisations, Science and Industry) and the MRCG and we’re delighted that the Department of Health and the Health Service Executive (HSE) are represented here today also.” Mr Watt emphasised that the MRCG is “trying to do our bit from the bottom-up”, but stressed that political leadership is vital in this area.

“It would be fantastic if the Minister for Health and Taoiseach took a similar stance to President Obama in relation to health research in general and also in terms of PPI in health research, in particular. We have so many skills in Ireland and all we need are the policies to be put in place.”

Philip Watt
Chairperson, MRCG & CEO, Cystic Fibrosis Ireland
Keynote Address: Exploring Possibilities

Mark Pollock, Collaboration Catalyst & Explorer

Philip Watt welcomed the Keynote Speaker, Mark Pollock, on the theme of ‘Exploring Possibilities’. During his address, Mr Pollock provided a poignant, moving and inspiring overview of his experiences with disability and his determination to overcome his challenges and act as a catalyst for improving the outlook for spinal injury patients in the years ahead.

Mark has been selected by the World Economic Forum as a Young Global Leader and has been awarded honorary doctorates from the RCSI and Queen’s University Belfast. He has raced to the South Pole and co-founded the global running series Run in the Dark, among a long list of other achievements, despite his blindness. Approximately six years ago, a fall from a building left him paralysed from the waist down and he narrowly escaped the death his doctors were imminently expecting.

‘Challenges choose us’

“I didn’t choose any of it,” he told the attendees.

“I made sense of it all by coming to understand that sometimes we have the luxury of choosing our challenges, but sometimes our challenges choose us. We all have our challenges; what we decide to do about those challenges is what we can actually control and take action, such as in conferences like this, where we can make a difference.”

Mark Pollock
Collaboration Catalyst and Explorer
He touched on the choices between “being a collaborator or a soloist” and “being a realist or an optimist”, telling the conference about his journey as a patient and interaction with different specialties. Referring to the book *Good to Great* by Jim Collins, he said: The part that stuck in my mind was a conversation the author had with a former prisoner of war in Vietnam… it wasn’t the optimists who survived the experience, because they kept thinking they would get out at the start of the summer, then the start of the next summer, and so on. When they didn’t, many of them became demoralised and died in their cells. The ones who survived were the realists, the ones who got up every day and looked at their lot and their difficulties, and just took it from there. I tried to apply that thinking as I wrote my blog, *Stream of Consciousness*. It’s attractive to be an optimist, but being an optimist can be a risky business sometimes."

Being a realist allows one to have both acceptance and hope, he added. “When I left hospital, I started to look more closely at what it really means to have a spinal cord injury… it strikes at the heart of what it means to be a running, jumping, walking human and makes us compromises of what we once were.”

Despite the seriousness of the subject matter, Mark delivered his presentation with a dry wit that was enjoyed by attendees. “Everybody here has brought the expertise in their own specialties. My specialty seems to be in accumulating disabilities,” he joked.

He explained that the challenges associated with spinal cord injury include secondary problems such as nerve pains, spasms and “massive doses of medication. These are things that exhaust even the most determined. This combination ultimately keeps seven out of 10 [people with spinal cord injuries] excluded from the workforce in Ireland and keeps four out of 10 living below the poverty line”.

While a cure for paralysis remains elusive, Mark Pollock stressed that human history is replete with examples of people becoming capable of the seemingly impossible. This inspired him to travel the world, seeking out pioneers who were pushing the boundaries in spinal injury treatment and ultimately a cure.

He described his visits to “aggressive physical therapy centres” in order to maximise his physical potential and allow him to take full advantage of any innovations that may emerge. One thing that emerged from this was a post-hospital rehab programme, “something that most people in this country don’t have access to,” he explained.

**Electrocution**

He began working with engineers and computer scientists in the field of robotics, however, all of these specialists were working in isolation. One of the more unusual treatments he tried was a form of spinal electrocution borrowed from old USSR athlete camps. A combination of this electrical therapy and pharmacological treatment had been successful in animals, he explained, but added that he has “little interest in animal studies — I’m more interested in research into humans”.
A first-of-its-kind treatment plan was developed and as the specialists began to collaborate with each other, an academic paper was published in September 2015 and a partnership was established between Trinity College Dublin and UCLA. Mr Pollock is now exploring funding to “get the concept out of research and into the clinic.”

“The point is this,” he told the conference. “We found brilliant people working in isolation, all excellent in their respective fields… but there are people who struggle to get out of bed in the morning and keep going and never get out of their house, and what we are trying to do is to find and connect people so that patients can access what I have access to now. Electrical stimulation seems to be fixing things like sexual function, bladder control and so on in every single patient they are used on. Movement and feeling is the next big step.”

He concluded:

“*The question at this conference, and the nature of MRCG, is to galvanise people towards common goals… if you keep your eyes on the prize, you can overcome any geographical or political problems and the fragmentation.*”

Mark Pollock
Collaboration Catalyst and Explorer
Increasing Patient Involvement in Research: Our Story

Katie Scott, Senior Patient Involvement Manager, Cancer Research UK

Katie Scott of Cancer Research UK, addressed the attendees on the topic ‘Increasing Patient Involvement in Research: Our Story.’ Ms Scott provided an overview of current PPI in cancer research in the UK, explaining that in recent years there has been a trend towards increasing PPI in medical research, and this includes a ‘consumer forum’ for patient representation and patient involvement in clinical studies groups.

“This has really embedded the practice of PPI in clinical cancer research in the UK,” she told the conference. “There has been a massive uplift in the attention given to patient involvement in medical research in the UK. This is an evolution from organisations just providing patient support, to actually involving patients and this is now embedded in these organisations’ culture.”

Katie Scott referred to the Shared Learning Group in the UK, a collection of peers who get together every couple of months to share their experiences and develop best practice guidance for the community. It was the first organisation of its kind to focus on such patient involvement.

She outlined how Cancer Research UK was previously seen as a “very cold, distant organisation” but in 2012, the organisation rebranded, which was “instrumental in changing how patients saw us.”
Katie Scott said her organisation uses a patient database to communicate with cancer patients on a monthly basis about the opportunities patients have to communicate and influence what Cancer Research UK does, and the organisation publishes this input on its website. There is also patient involvement on the funding committee, she added. But one of the biggest hurdles to overcome in this evolution was in the complex science involved in medical research and how patients might relate to it, Ms Scott explained. "We have been working with other people on this and the Grand Challenge initiative is a great example of this," she explained. This also involved consulting with patients on the kind of information they would be most interested in. "In the past, there would also have been a confidence issue, with people not knowing what to expect when they walk into a room full of patients... we do a lot of work upskilling staff and helping to build the confidence they need for patient involvement."

She said it is sometimes also necessary to educate people on the time and complexities involved in recruiting patients and touched on the issue of dealing with patients who are informed and actively seek out information on their conditions. "We have to think strategically about how we talk to patients and make them aware of the opportunities for involvement, and how they have the chance to influence the way we work," she told the conference.

"The language we use has been very important; we have talked about ‘value-adding patient involvement’ and making sure that people know we are not just doing it for the sake of it... we have made enough progress now to start looking externally at what the researchers that we fund are doing — this involves some 4,000 scientists, nurses and doctors across the UK — about 50 per cent of them do not really understand what PPI is, so there is a big knowledge gap there that we can fill."

“In order to raise money, we needed to be seen as much more relevant to patients and have a much more human face. Our board recognised the need to develop a patient engagement strategy... the area that my team works on is patient involvement. Even though we are late-comers to patient involvement, we have seen a massive change over the past couple of years in what we are actually doing.”

Katie Scott
Senior Patient Involvement Manager, Cancer Research UK
Public and Patient Involvement: Meaningful Participation

Anne McFarlane, Professor, Primary Healthcare Research at the Graduate Entry Medical School, University of Limerick

Next to address the conference was Professor Anne McFarlane of the University of Limerick (UL), who discussed the topic ‘Public and Patient Involvement: Meaningful Participation’. Professor McFarlane is a Social Scientist with more than 20 years’ experience and is Professor of Primary Healthcare Research in the Graduate Entry Medical School in UL. She is also known for her work with migrants, refugees and asylum-seekers.

Professor McFarlane spoke on the concept of partnerships in health research and the dialogue that is necessary to make this happen. She outlined a project to involve migrants in the development of general practice in Ireland and discussed the rationale for PPI. “The first rationale is probably the oldest one and relates to social justice,” said Professor McFarlane.

“The idea is to really include people and reduce health inequities. There’s also a more recent theme, which is efficiencies, which may be attached to consumerist ideology — if the health service is a public service, we need to listen to the consumers of that service to reduce wastage.”

She explained that the ‘efficiency’ theme also relates to research and said that often, research is conducted that can have little relevance in terms of public interest.
“There is a notion that if we involve patients in setting research priorities, we can use the funding more efficiently. And then there is the question of impact — getting evidence into practice is a major challenge and researchers who study that translational gap are very clear: if you have knowledge-users involved in research right from the beginning, it is more likely that the findings will be disseminated and will have some kind of impact.”

Anne McFarlane
Professor, Primary Healthcare Research at the Graduate Entry Medical School, University of Limerick

Professor McFarlane also spoke of the “worrying” perception of tokenism among the public when it comes to research, and described “the complex terrain of the language that is used”, but added: “I think it’s really positive that the Irish Health Research Forum has brought people together, and now we have a working definition of PPI — Individuals meaningfully and actively collaborate in the governance, priority-setting and conduct of research, as well as summarising, distributing, sharing and applying knowledge.”

Professor McFarlane outlined a participatory health research project based on the fact that Ireland’s population is increasingly diverse, with more than 200 languages now spoken here. She described the barriers to holistic care faced by both patients and GPs who do not share a common language.

The project involved seven migrants who were concerned about such issues, as well as academic partners and GPs, and examined the best strategies for communication between physicians and patients. The migrants themselves became peer-researchers in their communities, therefore eliminating the language barrier in research, Professor McFarlane explained.

“The migrants really valued the PLA [Participatory Learning and Action] approach,” said Professor McFarlane. She presented an overview of the research project, pointing out that the full paper is available at PubMed. “It can be very difficult to get an interpreter and a patient in the same room at the same time,” she explained. There were many revelations, not least around the difficulty in using family members, friends or receptionists as ad-hoc interpreters, said Professor McFarlane, but addressing these issues did provide clarity for the guidelines.
The James Lind Alliance Perspective

Beccy Maeso, The James Lind Alliance & Senior Programme Manager at the National Institute for Health Research Evaluation Trials and Studies Coordinating Centre (NETSCC), University of Southampton

Next to take to the podium was Beccy Maeso of the James Lind Alliance, who delivered a talk on ‘The James Lind Alliance (JLA) Perspective’. Beccy explained that the Alliance is based on bringing patients, carers and clinicians together into priority-setting partnerships (PSPs), designed to eliminate uncertainties on the effects of treatments.

“Research on the effects of treatment is usually led by researchers or funders. Sometimes, this doesn’t address the real concerns the patients themselves may have about their treatment. There is still quite a mismatch between what patients and health professionals want to see researched and what is actually being researched.”

Beccy Maeso
The James Lind Alliance & Senior Programme Manager at the National Institute for Health Research Evaluation Trials and Studies Coordinating Centre (NETSCC), University of Southampton
Beccy presented data to illustrate this mismatch and went on to outline the overall role of the JLA, including the fact that it values transparency highly and is inclusive of all groups, ensuring equality in participation for patients.

The JLA also has an international reach, ranging from Canada to the Netherlands, she explained. “That’s very interesting, to see how different countries are in different places when it comes to PPI,” said Beccy Maeso. “We have had to think about our methodology in working with them.”

She highlighted a quote from one participant of a study into mesothelioma, a condition caused by asbestos exposure. “This woman said: ‘After my husband died, I wanted to use my experience with this dreadful disease to try to help shape... further research for mesothelioma patients. I found it extremely refreshing that patients, carers, healthcare professionals and clinicians were all working together to identify the top research priorities’.

But it's not just patients who benefit, Beccy Maeso emphasised, as research has shown that the JLA process affects the way clinicians treat patients and positively affects outcomes.

She concluded by encouraging attendees to visit the JLA website (www.jla.nihr.ac.uk/about-the-james-lind-alliance/) to get further detailed information on the organisation, its methodologies and PSP process.
Supporting PPI Across the System - A Research Funder’s Journey

Anne Cody (PhD), Head of Pre-Award, Health Research Board

Anne Cody of the Health Research Board (HRB), spoke on the topic of ‘Supporting PPI Across the System: A Research Funder’s Journey’. Anne outlined the broad remit of the HRB and the range of research funded by the organisation in a variety of healthcare fields. She reinforced the Board’s commitment to promoting PPI within HRB-funded projects and outlined the contents of the HRB’s strategy document, *Research, Evidence, Action*.

“I think PPI in Ireland is still very much in its infancy,” Anne Cody told the meeting. “In formulating our strategy, we looked at international models, although you can’t just cut-and-paste these; they have to be context-specific… there are a number of really brilliant individuals who have been doing PPI for a number of years, but this is a small cohort and very much driven by individuals, so if you want to get beyond that, clearly something else is needed.”

Anne Cody outlined some HRB initiatives that can foster PPI, including some 110 joint funding projects with research charities, but added the caveat that “just because something is joint-funded with a charity doesn’t make that strong PPI and we are looking at ways to improve our approaches. The fact that we are coming here today to discuss PPI, and not for the first time, is great.”
She outlined a HRB survey of researchers and members of the public on how they could support PPI and showed that the main results include the revelation that there is a strong appetite for PPI. “Out of 148 researchers we surveyed, all but one said ‘yes’, they support PPI,” she told the attendees. “Another result showed that what people want most from the HRB is practical help [in PPI]. Also, avoiding tokenism has been a consistent message throughout both arms of the survey and that’s something we feel quite strongly about too.”

Members of the public were shown to be extremely keen to have an input into research questions, Anne Cody said, and the HRB used this data to inform what the Board funds and how it does so. During her presentation, Anne Cody also outlined the Ignite project, a funding initiative by the HRB of some €350,000 over two years to foster effective PPI. “This is about getting more researchers out there to support PPI and getting people to start thinking about PPI from the very beginning.”

“The key point is that the responsibility for PPI remains with the researcher. People will collaborate with and support researchers, and provide a sounding-board, but the main responsibility is with the researchers.”

Anne Cody (PhD)
Head of Pre-Award, Health Research Board

Having provided the meeting with an outline of the HRB’s decision-making process and funding philosophy, Anne Cody concluded by saying she is talking with the Board’s communications team about some awareness-raising events on PPI. She stated: “We will all have to see where this road takes us, because I think we are all very much on a steep learning curve.”
Patient & Researchers Panel Discussion: Experiences and Challenges

PANEL

Julie Power, Founder & Chairperson, Vasculitis Ireland Awareness

Dr Eamonn Molloy, Consultant Rheumatologist

Michael Griffith, First Chairman, Medical Research Charities Group and Co-Founder, Fighting Blindness

Dr Paul Kenna, Clinical Ophthalmologist, Royal Victoria Eye and Ear Hospital and Senior Clinical Research Fellow, Ocular Genetics Unit at Trinity College Dublin

Dr Marguerite Hughes, Vice President, IPWSO

Professor Louise Gallagher, Chair in Child and Adolescent Psychiatry, Trinity College Dublin

Alexis Donnelly, Person with MS

Professor Michael Hutchinson, FRCP Consultant Neurologist and Newman Clinical Research Professor

CHAIR

Derick Mitchell, CEO, IPPOSI

The final part of the conference featured a panel discussion involving both patients and researchers. The discussion was chaired by Derick Mitchell of IPPOSI, who introduced the panel.

In his opening remarks, Mr Mitchell said: “What I think we lack in Ireland is not the inspiration or the skills, but we need more practices, and I think the PPI Ignite award will help to generate some of those practices. There are existing practices that are led by patients or universities that we haven’t collated in a structured way, from the point of view of learning from some of the experiences and challenges.”
“The panel discussion today is about highlighting some of those practices that have emerged from patients and clinicians working together. I agree with Philip — we need the type of political leadership they have in the UK that has driven PPI to the level it’s at right now.”

Each member of the panel delivered their own experiences and provided their input, based on their own perspectives. Ms Power said she founded Vasculitis Ireland Awareness through frustration and described herself as “very lucky” to have Dr Molloy involved in the clinical input of her endeavours. “We are currently involved in a five-year project to identify flares for the disease,” she revealed.

Dr Molloy added: “The key point for rare diseases like vasculitis is that organisations help to link patients together, so that they don’t think they are the only person with that disease; there may also be a clinician who has only one person with a certain type of disease. Helping to create these links is really important — between patients, clinicians and centres of care.”

Mr Mitchell noted how both patients and clinicians have been “empowered” by such links and interactions.

Michael Griffith, who has been working with Dr Kenna for many years in the area of retinal conditions, praised the work of the MRcG, describing the “wonderful feeling” in seeing the organisation’s progress. He described his journey after being diagnosed with retinitis pigmentosa in his late teens and outlined the evolution of Fighting Blindness. “I think that if we had more people with Mark Pollock’s spirit, people who keep pushing the boundaries, we could achieve results a little more quickly,” he said. “My take away message would be, I’d like to encourage those involved or working in research to push, push, push and don’t take ‘no’ for an answer.”

Dr Kenna added: “Some of the work that I’ve been doing just couldn’t have happened without patient involvement… I have come to know hundreds of patients over the years and their involvement has been absolutely crucial in developing treatments.”

“We are undergoing a gene sequencing project to genetically diagnose Irish patients to get them ready for the prospect of gene therapy… the trial that was involved in that is a very strong example of patient involvement and the support of Fighting Blindness.”

Dr Hughes and Professor Gallagher spoke next, with Dr Hughes providing an overview of the rare disorder Prader-Willi Syndrome (PWS) and her 12-year-old son’s experiences with the condition, as well as the general lack of awareness on PWS that Dr Hughes encountered in the healthcare system. She also outlined the methodology of a major survey by IPWSO on all aspects of the condition and its treatment options, in an effort to raise awareness.

“We hope that the full results will be published in the next couple of months and they will be published on the IPWSO website [www.ipwso.org] if anybody would like to take a look at them,” said Dr Hughes.
Professor Gallagher added: “My involvement with patients and families in research has been very enriching, and certainly I would say, specifically to the PWS project, the involvement of an advocacy group has been vital.”

Last to address the meeting were Alexis Donnelly and Professor Hutchinson. Alexis Donnelly, a qualified researcher in his own right, said: “I feel that my journey with PPI is just beginning, but I have learned an awful lot from the people who have spoken today. The problem with MS is that while there are about 15 new medications for it, there hasn’t really been an awful lot of research done.

“We don’t really know what kicks MS off and it is very hard to measure whether a medication is really making any difference in progressive MS, because you need to wait a long time to see if your disability is progressing or not.”

He described his involvement in an international initiative, the Progressive MS Alliance, saying: “I’ve been lucky to be involved in the Steering Committee… it’s incredibly exciting, incredibly empowering and incredibly humbling. As many other people have said, you can bring the punters and get the ‘view from the pew’, and that really helps the research. It’s fantastic to see the interaction between researchers and patients as equal partners.”

“In Ireland, we are probably some way behind world leaders in PPI, but we have two good things going for us — we can learn from experiences, what to do and what not to do, and we have a genius for networking.”

Professor Hutchinson added: “We have a relatively low level of basic research into MS in Ireland and a lot of what is done has been industry-driven involvement in trials. Clearly, the need for people with progressive MS was there and the most significant event in MS in the past five years has been the Progressive MS Alliance — we are extremely proud that Alexis is our Irish representative. The future looks good for advancements in progressive MS and that’s down to involvement between researchers and people with MS.”
Conclusion

Philip Watt concluded the conference by thanking all the speakers and those who attended. “The talks we have heard have been both informative and extremely moving,” he told the attendees. “You can rest assured that the MRCG, IPPOSI and all those here today will be bringing forward the PPI agenda in a very strong way and it’s extremely encouraging to hear that there is funding and support for this.”

Please visit www.mrcg.ie to view the conference briefing paper, full speaker biographies, presentations, videos and photos.
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