

AMRC Statements & Speeches

Speech by Simon Denegri, Chief Executive at AMRC, to the INVOLVE Conference: Wednesday 17th November 2010

The rise and rise of public involvement: what's stopping us?

Good afternoon ladies and gentlemen and thank you Nick for that introduction.

Perhaps I can begin by taking this opportunity to congratulate Sarah, the staff and my colleagues at INVOLVE for pulling off yet another fantastic conference this year.

I feel very privileged to have been asked to give this keynote...or should I say endnote speech at the conference. And I feel you have done half my job for me already.

What better evidence of the rise and rise of public involvement than the last day and half? More delegates than ever before, truly exciting examples of innovation and impact, new insights, robust discussion as ever and a sense of spirit and energy that is inspiring.

Peter Beresford in his keynote speech at the last INVOLVE conference said he was an eternal pessimist driven to optimism by events there. I am eternal optimist who tends to always 'turn their face to the sun' as Virginia Woolf put it. Whatever our outlook on life I think the great thing about INVOLVE conferences is that, as Charlotte Bronte said, they encourage us to 'keep looking upward' rather than always backwards or forwards.

And over the next twenty minutes I'd like to look upwards with you, to offer some reflections on our next climbs, the challenges and opportunities associated with them, and how we move together to meet them.

One last thing: I'm conscious that conference fatigue may be setting in for some of you so I thought you might appreciate pictures to look at rather than endless slides full of words, some of them taken by me over the last day or so.

Think of it as an early phase trial of a new medicine called anti-PPT or anti-PowerPoint.

And what better way to start than with a picture of two Prime Ministers on their first day in office.

Context is everything

INVOLVE has always been responsive to what is happening in the world around it – context is everything as they say. So it is perhaps worth looking outside this room at what has changed and is changing for us.

When INVOLVE had its first ever conference, Tony Blair had been in office just over a year. Over the next decade there was a sea change in the way that government looked at patients and the public, and the importance it attached to research.

Patient choice, the establishment of the National Institute for Health Research (NIHR), the focus on improving the way we do clinical trials in the UK including public involvement, record investment in science. Not only have we been able to benefit from this environment but we have had a strong hand in its making.

However, the context for our work is now much more uncertain than it has been for a long time. Relief rather than celebration greeted the spending review settlement for science which got off lighter than others. Medical and health research is in a stronger position than most and we should welcome the fact that NIHR has committed to a budget for PPI over the next three years. But research will not be immune to the impact of what is happening across what people like to call the ‘whole system.’

Cuts to university funding which will undoubtedly impact their research productivity; local authorities face significant cost pressures which can only serve to accentuate what has been a perennial of INVOLVE conferences about the status of social care research. Whatever assurances people might give us...we know that public involvement and activities like public engagement are more vulnerable than most in times like this.

Nothing about us, without us

Then there are the reforms to the NHS embodied in the White Paper ‘Equity and Excellence: Liberating the NHS.’

Shortly, the legislation to enact these reforms will begin its passage through parliament. We have been promised a radically different health service in which ‘No decision will be taken about us, without us.’

It sounds good. But let’s be flattered rather than fooled by this statement. At the very least, we need to be asking deep and searching questions of it.

Aside from concerns about the scale of reform and feasibility of delivery in such a short space of time, there are two particular issues from a patient in research perspective that I can see and which we need to be acutely aware of.

The first is the inherent risk for research of putting GPs in the driving seat of how the NHS is run. The number of research intensive GP practices is small, the attitudinal and resource barriers within the profession to discussing and involving patients in research significant. As one patient who took part in some focus groups that AMRC ran on behalf of UKCRC on patient the feeling is already out there that: ‘Seeing the GP is more of a production line than it used to be.’

The second is that, at present, the Department of Health has yet to say how it will incentivise research in the new system which will basically rely on a range of tariffs for different activities to encourage providers to do them.

Without solutions to both, the upshot may be – as my mum would say – ‘the mind is willing, but the body is not.’

Champions

But I do believe INVOLVE and all of us can make a real difference to this environment by prodding the Government’s thinking very hard. But also by ensuring that we not only have a growing number of champions as in this room but a growing number of champions who are in the right places – whether it be on NHS Trust Boards, the new NHS Commissioning Board or in GP Commissioning Consortia.

The AMRC/INVOLVE and JLA event ‘Building on Success’ this spring highlighted for me that while the grassroots of public involvement is strong we need to see many more champions in the sorts of forums I have just mentioned, the sorts of places where decisions are being made on a daily basis which have a direct or indirect impact on public involvement and research of patient benefit. And that leadership work extends to other areas such as journal editors and the degree to which public involvement is reported in peer-reviewed articles, somewhere where we have not seen as much progress as we would have liked.

Regulation is all you need

The second opportunity we have to make a real difference to the future of medical and health research lies just around the corner.

Given the technical complexity of modern government, regulation and regulators have become an all-important mechanism for ensuring good government that is in the public interest. They also have a major role in shaping culture, attitudes, the colour and tone of how a sector works. And research is no different.

As many of you will know, the Academy of Medical Sciences is conducting an independent review of research regulation which will report around the run of the year. It has been prompted by widespread concern about the way in which regulation is currently conducted and how it holds back progress. Nick and others have given oral evidence and AMRC and INVOLVE hosted a workshop a few weeks ago to provide a patient perspective on some of the issues that concern us most in this room. A single regulator for research is highly likely.

But whatever the final proposals from the Academy report, we need to use them to press the Government hard for stronger models of public involvement in research regulation from top to bottom.

There seems no excuse to have a system of regulation in place which is out-of-kilter with how other parts of society are regulated where the consumer is seen to have an important if not equal part to play in ensuring public trust and confidence. And I think we need to make clear how costly it could be if regulation is not seen as a shared endeavour between researchers, patients and the public.

After all, we are all essentially wanting the same thing don’t we? – as one of the participants in the workshop I just mentioned said that our goal should be to see the

National Health Service re-named the National Health and Research Service (NHRS), that we should carve it in stone above the door of every Trust.

Big Society, Big Questions

Before I move on I hope you will forgive me one quick but relevant aside about the Big Society.

On the one hand, with its mantra around participation and involvement the Big Society would seem like manna from heaven wouldn't it? On the other, its underlying principles of self-determination and self-definition feel like a cover for drawing back the state from its role in providing a framework for what you and I and many others can do in the name of inclusion through funding, intervention and support.

The Big Society is a poorly articulated and shoddily crafted concept and I'm a little disappointed with the way the third sector has seemingly rushed unquestioningly to redefine itself in its image.

I rather agree with one of my colleagues from another umbrella organisation who said that, in the first instance, we need to seek greater precision while contesting the current arguments behind it with evidence of the value of collectivism.

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So that is the context and I hope you don't mind me taking time to reflect on it at some length. After all, if we are to look and climb upwards we must have some sense of the weather that is beginning to move in on us.

To finish I'd like suggest three maxims for how we continue to grow strong in the future and this is the moment where I'd like to reflect a bit on the role of the charity sector.

Charities and public involvement

Those of you who know a little of the history of public involvement and INVOLVE may have worked out from my biography that I worked with Harry Cayton at the Alzheimer's Society's at the time that Quality Research in Dementia (QRD) was being established.

That was in 1997. The year before, 1996, the Society promoted what was probably one of the first ever charity-driven public awareness campaigns focused on research entitled '*Opening the Mind*' for which it received a PR Week Award for best charity campaign of the year. Both have been formative experiences for me in demonstrating what can be achieved when researchers and service users work together with the same goal in mind.

When I became chief executive at AMRC ten years later I confess I was surprised not by how much that work had been built upon and improved, but how little it had permeated the thinking of medical research charities in a meaningful way. Many

could point to 'lay' people – I hate that term which implies taking things lying down – on their peer review panels, but few had really advanced beyond it.

There are lots of reasons for this, but I think it is probably true that the overall perception of AMRC and its members was that we had put all our eggs in one basket – namely 'science,' that we were a little disinterested in public involvement. That is changing fast.

Public involvement – the 'how' rather than the 'why' – is now one of the most frequent questions that we get in the office from our members. Some of you may know that last year we published our first report 'Natural Ground' based on the experiences of charities in implementing patient involvement. With the help of TwoCan Associates we are this week launching a web-based route map to help charities design patient involvement programmes. More members are coming forward expressing an interest in the James Lind Alliances partnership model of identifying treatment uncertainties. And we will be asking much deeper questions of charities about how they implement patient and public involvement when we audit their peer review practices in the coming month – the basis of the AMRC quality mark.

Stay close to your public

This change has lots of underlying causes – a recognition of how public involvement can enhance research, a concern to demonstrate greater value and impact for their research funding. But a more basic, primal urge underpins it and that is a very real desire and need of my member charities to stay close to and responsive to their respective public.

And that is my first, very simple message this afternoon of the need for us to stay close to our public and our values whatever else is happening out there.

It is what got us here, it is what drives our sense of purpose and vision but it is also our competitive advantage over politicians and policy-makers who feel deeply vulnerable and neurotic about their disassociation from the public and recognize that modern government is impossible without working with partners who can.

During the spending review the patient voice was highly influential within government in the ways it thinks about, and defines the impact of, medical and health research. We know, for instance that the Times Letter that 78 of our member charities signed in the days leading up to the Chancellor of the Exchequer's announcement had an impact on the final decisions. And I could give you numerous other examples of where it made a difference such as the 'Science is Vital' campaign or in the countless case studies we put forward of where research was making a difference to patient lives.

So, as well as not losing sight of why we were created in the first place, we shouldn't underestimate what we can achieve in the future nor miss the opportunities that arise to transform things for the benefit of both research and patients and to challenge policy and its underlying assumptions by being too inward looking.

Connectivity

The second message is what one might call connectivity...

One of the observations I have made elsewhere is that – as a movement – we have grown organically and messily through the years. There are strengths inherent in this. But perhaps one of our challenges for the future is also how we connect our many parts.

One of the things I have become acutely aware of in recent years is how much is going on now in the name of public involvement across the UK: from patient networks in the charities to public involvement clinical research networks. And my sense is that their development is reaching beyond what we can rely on in terms of word-of-mouth and personal contacts.

So, perhaps a question of how we organize ourselves for the future without necessarily talking organizational shop is a question we must address sooner rather than later.

We have the same challenge at AMRC of course, with many different communities of practice, formal and informal networks, disease specific groups of charities – all drinking from different pools. The trick is in encouraging them to recognize that all these pools would not exist if it were not for a central reservoir or reservoirs serving them such as INVOLVE. And, in those instances, where one has a commanding funder to enable others to endorse to point and to tell the story from one step remove. And this is where I believe partnership – my penultimate message – comes in.

Partnership

As you know, I sit on the INVOLVE strategic alliances group which is tasked with identifying and working out how we work better with external partners.

But, as charities begin to come of age in public involvement in research, I feel we have only begun to scratch the surface in terms of what INVOLVE and AMRC and many others can achieve in partnership. We need to think of partnership not in terms of a single initiative but how we can make it a deep and long-lasting marriage. As Barbara Streisand said to Robert Redford ‘We could be so good together.’

Next year AMRC will be looking at what it wants to achieve over the next five years and I want public involvement to be one of the strongest components of that plan. So, I need you to push us, to prod us and to work with us and, essentially, I want you to be part of that review but also an important part of how we implement it.

In future, perhaps our task is not to think of all our partners in the same way as we sometimes tend to but to think about their relative value and how they fit with our focus and purpose.

Persuasion through impact

My final message is that we must continue to seek to persuade through evidence of our impact as a community.

I, like you, am aware that we still have much to do to convince skeptics and critics. But you know, as the head of a membership organization, I am used to dealing with divergence of opinions – often strong ones – on most issues. And it is possible to find ways forward, the art is finding areas of common ground and using each win or identifiable piece of success to build ever wider confidence.

AMRC's 'Natural Ground' report to which I referred earlier has been successful, not just because it demonstrates to charities what is achievable but also because it plays on their concern not to be outdone by their peers.

Similarly, with skeptics we need to remain positive, persistent and patient in constantly providing them with the evidence of how public involvement makes a difference and why it makes or can make UK research better than others. Sometimes it will also mean thinking carefully about our messengers. But we have seen examples of this in abundance yesterday and today.

Our task is to capture it, to package it, to disseminate it better, more widely and in ways that these audiences understand. That is going to be particularly important with the new Research Excellence Framework and its impact assessment, and we have a powerful hand to play in positioning ourselves as part of the solution for institutions who will need to demonstrate it to be rated as world-class.

Conclusion

In conclusion, I hope that I have succeeded in at least leaving you with some messages and questions to think about as you travel home, the need to:

- Stay close to our public and original purpose
- Connect our many different parts
- Create champions and leaders
- Develop our partnerships
- Persuasion through impact
- Challenge policy and its assumptions

Citizens

Socrates famously said that he was not a citizen of Athens or Greece but of the world.

The most basic definition of 'citizen' is 'member of a community.'

And as I looked back on previous INVOLVE conference reports one of the things that struck me most was indeed the growth of a distinct community now active in the

name of research for patient benefit; but also one that draws its strength from many different communities.

The first INVOLVE conference was attended by less than half the number we have here today. This year's event is notable for the number of service users – far more than ever before I believe. Not to mention the growing number of researchers, research managers, patient and public involvement leads and others who do more than just one of these things. As a member of INVOLVE I hope that these last two days have provided an inclusive forum for all of you to both learn and share.

Being realists rather than optimists or pessimists, I think we all recognize that we will never have enough resources to do the whole job in hand but I hope I have given you some food for thought (ahead of thoughts of food) on our climb from here in, as Socrates said loosely speaking 'our devotion to the conditions that support public involvement.'

Thank you.