**INVOLVE Conference 2012**

**Transcription of Final Session: Final discussion and Endnote speech**

**Alison Faulkner**

I’m absolutely delighted to have this opportunity to make just a few notes, take a few ideas that I’ve picked up from the Conference at the very end of the Conference today before introducing you to Simon Denegri, the Chair of INVOLVE, who will complete and finish the Conference for us.

You may well be wondering why me and I am too. It could be anyone of you standing up here and saying: “Well this is what I heard people say.” I’ve been involved in INVOLVE for quite a long time, until recently when they threw me out tragically, but now I’m an associate member so that’s something to be grateful for. As a user of mental health services, I began my two careers at more or less the same time, as a researcher and a service user in my early twenties. And my experience with INVOLVE has been a very long and happy one and I hope it will continue well into the future.

I think with a couple of people here today I felt that public involvement in research has very much come of age. I think we felt today that this Conference has led to people talking a bit more, debating a bit more, having a bit more critical debate amongst us rather than perhaps necessarily just trying to agree with each other about yes it’s a good thing. We’re starting to look a bit more critically I think about what it really means and I think that was reflected in the Soapboxes as well. People saying: “Actually I don’t really like the term PPI.” I hate, lets get rid of it, but unfortunately it’s there at the moment and so we have to put up with it, but I think there were some really good debates, really good discussions and these are a few of my thoughts. As I say, these could be any of yours and if anyone whose session I’ve been in today hears their words coming out of my mouth, then I hope that they will be quite pleased about that rather than thinking I’ve stolen their words. But, “Never forget why you’re here” was a phrase that I picked from Derek Stewart actually in his session. “Never forget why you’re here”. And I think I feel very, very strongly.

And Iain Chalmers introduced us to the idea that we should be more angry and I think actually anger can be such a good thing and such a motivating force but it’s not always easy. But I think that anger for me started many years ago when I felt that research doesn’t ask the right questions and that was why I came to get involved in the first place. So Iain Chalmers said anger - there’s wasted research, wasted time and money out there. And this brings also a bit of a dilemma to me about relationships because - I’m going to dot around those little themes from time to time, this is the only slide I have so I won’t be here for long you can tell - it brings a dilemma into the idea of relationships and public involvement I think because we try to work together. If we want to have a really good meaningful, a really productive partnership of public involvement, of service users coming into a research environment, an academic environment, perhaps we need to get on in order for that to work. So what do you do with the anger when it comes up because there are incidents of anger within individual projects where people are not happy with the way things are going. But there’s a lot of things to be angry at the moment. We’ve also heard in one of the Soapbox sessions at lunchtime that there’s a lot of people right now across Europe becoming very angry about austerity and some of the people that I follow on Twitter, the disability activists that I follow on Twitter, are right now tweeting a lot about the anger, about the work capability assessment and various welfare benefits changes that are taking place, the reforms, the cuts to services. So there’s a lot to be angry about out there and so yes, I think it’s really fantastic to remember to be angry sometimes and we can all make a difference. And that was another thing that came from one of the Soapboxes today, every one of us can make a difference. And I hope that we can, particularly after this Conference, go away and really feel that the strength and the power of that when we leave today.

So another thing that I thought that I felt a bit angry about, and this is a big subject for me and I know that this is my personal take on the Conference, was to think about the medical model and the extent to which I immediately started to think, oh that’s really interesting because one of the things that Iain Charmers was saying that the medical establishment itself is falling in with the industry agenda, that we’ve seen so much wasted money, wasted time, resources on research that could have worked

better if only, not just if only there were more public involvement actually, but if we were actually, all of us, challenging that agenda in different ways. But I think maybe the NIHR might be also adopting that medical model too, to a greater extent. It still dominates I should say, I don’t really mean adopting it, I think it still dominates the debate. Somebody that I worked with about 20 years ago was here yesterday and she said she felt a bit defensive because somebody quite a few people were polarising service users and researchers very much, again maybe talking about that element of anger that might come up between people with very, very different views, different perspectives and different models of looking at the world. And she found herself feeling quite defensive, and it made me think is that actually happening, is there something more that we need to think about in relation to that? And I think the problem is that a lot of the research that we are looking at, that happens through the NIHR, is dominated by the medical model and that is one of the problems I feel also with the way in which we can measure impact.

I’ve attended a couple of sessions that are looking at impact and I was stimulated by the idea that we are taking a bit of a medicalised model approach to measuring impact to PPI and measuring the impact of PPI. And what about looking at PPI as a social phenomenon, as a right actually rather than as something that we need to measure and find evidence for? And I know that debate goes on within the whole world of looking at impact but I just thought it was another useful way of having a different perspective on things.

Culture yes, there’s very little we can do to change culture when we are working within a particular research project or a particular research institution, but it came out from several of the sessions that I attended that the culture and the leadership can make a huge difference to the success of involvement, to the very nature of the involvement. And we just saw, there’s just such a huge diversity of projects here today, not just today but yesterday, a huge diversity of projects and listening to lots of different ways of doing things as well as different cultures. But sometimes it comes back to the idea that you cannot actually change the culture sometimes, it’s very, very hard to change the culture.

And one of the barriers that brought up for me was a barrier that often comes up in research projects that I’ve been involved in, where the Ethics Committee can be the barrier, and the traditional barriers and structures are still very much there, that make it very difficult sometimes for public involvement to take place. So in one of the sessions that I was in um, they referred to the difficulties of Ethics Committees and somebody talked a ‘Survivors Committee’, it’s the ‘Survivors of Ethics Committees’ which I hadn’t come across before but I rather liked that actually. Another area where the medical model came up for me was in a session that was supported by an RDS, Research Design Service, and I must admit I’m not at all familiar with Research Design Services, so I feel I learnt a bit more today about maybe I could go to a Research Design Service with an idea and actually start to think about how I might do my own project and I hadn’t really thought of it like that before I must admit. So I was very enlightened by this project, which included one particular charity who I have come across before which is a small and really powerful, vibrant charity called Thyroid UK, who are trying to do some research that really does challenge the medical establishment and consequently are really coming up against massive hurdles to get that research done in any way. And they’ve done some research in the past in which they’ve managed to overcome that by getting some private funding or funding it through their own charitable funds. But it did strike me then as well that that is such a massive thing. Sometimes we are angry because the services, the treatments are not working for us and that’s why we want to do research into these areas but it is still so difficult to get more than a tiny pot of money to do the research that is like that, that is really challenging the medical establishment. I don’t want to be too negative, we’ve got some fantastic examples here and so I don’t really want to go too far down that pathway but I just thought it really struck me in that session how when we’re really challenging the medical establishment how much more difficult it is to get there, to do anything.

So a final couple of thoughts. It also often makes me think, this Conference, about issues of identity partly because of that comment from the colleague of mine about being a researcher and feeling a bit defensive about some of the comments that she’d come across. And I was thinking yes when I was doing research some 20

plus years ago and someone had come and challenged me to involve service users then, maybe I wouldn’t have seen it in quite the same way. My journey has been a different one but I think I would have probably found it quite challenging too then. So I found myself thinking about identity in relation to that but also in relation to some of the debates that came up in several different sessions about professionalisation of service users, professionalisation of lay people. When you get a bit of training does that make you a researcher and make you not a lay person anymore? And that’s certainly a dilemma that I have lived with over a number of years now because I have a research identity as well as a service user identity. I think it’s a particular responsibility of mine to try and enable other service users to come in and join me to train people sometimes, to work with people, support people, to be involved in research. And that’s more and more what I do these days, which has also led to some frustrations because I’m often not involved in doing the research itself, which is an interesting one as well.

Finally, it is so much about relationships and I came to this Conference knowing that I would meet some old friends because of having worked with INVOLVE over a number years and it’s really wonderful to be here and to have that opportunity. But I’m also just mindful of another Soapbox session where Sally Crowe, I think, was talking about relationships and how when she comes to this Conference there’s more hugging and then Derek Stewart picked up on that and I think he mentioned kissing but I wouldn’t like to go too far down that route obviously! But so much of it is about relationships, it’s about how do we work together when we have very different perspectives, very different experiences of the world, often very different agendas, different all sorts of things, different, I don’t know, bank accounts also, £3000 overdrawn, oh no! So just to finish on that note then, “never forget why you’re here”, and I’ll go back to that. I was going to call it: “Who’s research is it anyway?” but I thought that was a bit old hat. “Never forget why you’re here.” You’re here because you want to make a difference and that’s so, so powerful and I think there’s so many of you in the audience who have come here because you do really want to make a difference and so do I, and I think it’s a really, really fantastic opportunity to be here today.

And so finally I’m going to pass over to Simon Denegri who will be giving, I

know, an excellent end note speech. Thank you.

[MUSIC: JAMES BOND THEME]

**Simon Denegri**

Thank you guys. That’s not because I think I’m James Bond, that’s to convey the sense of mission that we’re on and I think Alison set us up very well for that. Good afternoon ladies and gentlemen and Alison thank you so much for sharing with us today your perspective on public involvement and life as a member of INVOLVE. And I’m glad you are continuing as an associate member and I think the warmth of the reception just shows you the high regard in which you’re held amongst your friends and colleagues in the room. And thank you for introducing me and agreeing to Chair this final session of the day in our Conference.

Can I also just begin with a few other thank yous. First of all, to say it’s been a privilege actually to work with members, old and new, and the many supporters of INVOLVE in this room since I took over as Chair from Sir Nick Partridge last year. I’m sure you all share my deep gratitude to Nick for his leadership and for helping us to lay down such solid foundations for public involvement in the UK, and for guiding us with such wisdom over the last decade. I actually saw Nick last week and he wished us all the best for a successful conference. And, as you might expect, Nick continues to champion public involvement very forcefully in various forums up and down the country and across research and he continues to be a very strong ally to us.

Also to Sarah and the fabulous team in the INVOLVE office, my thanks for all that they’ve done to support myself but also you and many others in this room. Two years ago, when I spoke at this Conference, I put up this picture to convey what it feels like to work in the INVOLVE office and how life must feel like sometimes. Well, this year it’s probably felt a little bit as if the Chair might be actually flying that crop sprayer and so I would like to thank them, for their very great patience over the last 12 months. Now we have to do a few presentations before we get down to the main business. The first one I’d like to make is to Stuart Eglin who has been the Chair of our Conference Group. Stuart, you’ve done an absolutely wonderful job in bringing to life a vision for this Conference which has made it one of the most successful, I think the most successful, that we’ve ever had and I’d like to thank you very much for that and ask you to come forward and have a little gift given to you.

[APPLAUSE]

**Simon Denegri**

The second one is to Maryrose who, within the staff group, has led the organisation of this Conference and Maryrose has been just fantastic. And each day up to the run up of the Conference I say: “It’s going to be brilliant, it’s going to be brilliant.” And it has been, so I’d like to thank Maryrose Tarpey also for all her work on the Conference. And Maryrose we have a little thing for you too if you’d like to come up.

[APPLAUSE]

**Simon Denegri**

And also to Sarah Bite and Helen Hayes who’ve played a huge part amongst the staff to make this Conference happen, and they’ve both brought brilliant skills to it and I love working with them. So Sarah and Helen, thank you very much and please also come up and get a little gift from us.

[APPLAUSE]

**Simon Denegri**

Right, no more kissing okay? Right, one last thing to do: Bad Pharma winners. We have in this room four lucky winners of Bad Pharma and I’m going to pull them out of the box now, or I might ask Alison to do that, so here we go.

**Alison Faulkner**

I might pick out my own name.

**Simon Denegri**

You might do.

**Simon Denegri**

Sophie Staniszewska. Obviously I’ve signed these ‘Ben Goldacre’ as you might expect. Right we’ll leave yours there Sophie. May McCann.

**Simon Denegri**

And the next, shall we do the next?

**Simon Denegri**

I hope you react like that to my speech, I really do. Karen Keates. And Louise Worswick. Louise Worswick. Now we made a rule that we wouldn’t present the prize to someone who wasn’t here so we’re going to do a re-draw.

**Alison Faulkner**

Oh excellent, somebody’s got to carry it home with them. What did you say?

**Simon Denegri**

I might win it.

**Simon Denegri**

Caroline Carr.

**Alison Faulkner**

No?

**Simon Denegri**

Okay we’re dwindling now.

**Alison Faulkner**

I’m here, I’m here.

**Simon Denegri**

You’re here. Third time lucky. Toby Brandon. Oh my goodness. They’re falling out the box.

**Alison Faulkner**

Oh sorry.

**Simon Denegri**

Dean Smith.

**Alison Faulkner**

We’re going to be here all night.

**Simon Denegri**

Alison Ford.

**Simon Denegri**

Alison here, Alison Ford? This doesn’t happen on the National Lottery, I tell you. Right, Sue Hadlow. Are you having a joke with me?

**Alison Faulkner**

I’m now going to choose one.

**Simon Denegri**

Choose one.

**Alison Faulkner**

Start reading them.

**Simon Denegri**

Alison chose one. Tony Sargeant.

That was really quite stressful, I have to say. I thought that would be really simple. Two last things. Thank you to you. You’ve been a great audience and delegates over the last two days. I know you’ve had to be patient at times but I’d like to thank you for that patience but also to all the many presenters, the people who asked questions, the people who made comments. I think it’s made it a really vibrant two days, so thank you. And to Professional Briefings. I work for Professional Briefings an awful lot and I think they’ve done a brilliant job of pulling these two days off so thank you to Professional Briefings as well.

Right, the main business. So ladies and gentlemen, there I was on Saturday afternoon at the pictures watching the new James Bond movie Skyfall. This was obviously background research for this day of course, listening to Adele dolefully sing “This is the end”, which is the opening line of the film’s signature tune as I’m sure you know. And, as you do at these moments, I thought about public involvement in research. We’re certainly not at the end, I said to myself, but we’re definitely not at the beginning. Perhaps you could say that we are at the end of the beginning. We certainly look in better shape than 007 looks at the beginning of the film. But perhaps I ought to come to an INVOLVE conference and, a bit like Q, issue

everyone a PPI pistol for instance or a lay review stun gun, or better still an Aston Martin to helps us on our way. So here’s a standard issue version of the INVOLVE Aston Martin and what it looks like in terms of the invisible version just in case you’re a bit worried about where you’re going to find it in a car park. Actually, you might have read scientists have developed an invisibility cloak today, I read on the BBC news. Anyway you’ll get that free in the next newsletter and we’re obviously going to get the Department of Health to pay for that.

But seriously not unlike 007, while the essence of our mission which is about putting patients first in research, has not changed over all these years, the context certainly has. And more so today than perhaps ever before, and that’s why I said yesterday after seeing Sir Iain Chalmers’ incredibly powerful and provocative keynote speech, that I thought this would be one of if not the most important INVOLVE Conference for many a year. Since I spoke at the last INVOLVE conference in 2010, we’ve had a spending review in which health research has faired comparatively better than most other sectors, but we’ve also seen a train of legislation in health and social care that’s thrown up many anxieties. The boundaries of research and how it’s conducted have also changed, and the public’s role at these margins is often undefined at best and ill considered at worst. And so we can be forgiven for feeling a little shaken, stirred or even both at various times. But meanwhile, we’ve also been constantly changing attitudes and the way things are done and I think that’s been amply demonstrated by events here in Nottingham, and this is where we started our two days.

So this is a Wordle of the poster titles in the abstract book, the conference programme. And if you strip away some of the most obvious words like ‘involvement’ we begin to get a little bit of a sense of our pre-occupations before the opening session, so we start to see things like ‘developing impact’, ‘development’, ‘study’, ‘exploring’, very interesting indeed. The enthusiasm that’s come over across

Twitter and in the general chat around the Conference hall would suggest, I hope, that people have come away inspired by what they’ve seen, and also inspired by the new connections that we’ve made and also old ones refreshed. We know we’ve achieved a great deal but we also know that there is much more still to do, much, much more.

Even Dame Sally Davies or should I say the CMO to continue the James Bond analogy, says as much and this is what she had to say when I asked her about it a few months ago at an NIHR Trainees Event. Can we have the film please? This might take a few seconds.

**Film - Simon Denegri**

Since I’ve got you here and with one of my other hats on here … [LAUGH]

**Film – Dame Sally Davies**

Oh dear.

**Film - Simon Denegri**

I wonder whether I could ask you a little bit about the importance of public involvement to you. Because of course there is a difference between taking part in a trial for instance or being engaged in terms of raising awareness. And the importance to you of involvement of patients because of course involvement of patients in communications is vital to getting the message right. And I wonder

whether you wanted to have a few words about public involvement?

**Film - Dame Sally Davies**

Well I think there are a number of stages of public involvement and engagement and it’s one of the core principles of NIHR that the public and patients should be involved at every stage. So for me it started when we were going to fund a rheumatology trial and, and all the end points were things about sedimentation rates and cytokines and a patient said to me: “But I don’t care about that, what I care about is can I get up in the morning? Can I make my cup of coffee? Tea actually. And can I function?” So we put those end points in. It made no difference to the scientific end point but actually it showed that however good the science was, did it work for patients? So I learnt that. But I think, I feel broader and it goes back to that view I expressed earlier that tax payers pay for what we do, we are accountable so they should have a voice. And we have, as you know, public and patients on every committee - prioritisation, grant awarding -every single committee because it is right and it is a voice that should be heard. So I believe in it passionately and from the research perspective we lead the whole world in it actually. People come to meet INVOLVE and see how they do it and hear from us about our passion for this and how we see it from the top.

**Film - Simon Denegri**

Yes, I was in Denmark a few weeks ago to launch the public involvement version of INVOLVE there and they think we live in the land of milk and honey and obviously I said yes but [LAUGH] we do, do well at this but we can do an awful lot better.

**Film - Dame Sally Davies**

Yes we can do more.

**Film - Simon Denegri**

An awful lot better.

**Film - Dame Sally Davies**

Yes.

**Simon Denegri**

So in terms of the many things that you’ve raised over the last two days I can assure you that when Sarah Buckland and I go to the NIHR Strategy Board tomorrow we’ll be coming up with a long list of the places where we need to do an awful lot more and get an awful lot better. In fact I wonder if, in terms of the evolution of public involvement, where you’d place us on this picture, which I’m sure many of you have seen many times in text books, etc. Standing tall perhaps? Some way off inventing the wheel I think? On the other hand it might just be that we’re about to light the fire that transforms our health research systems so that it truly puts patients first.

If we’re clear about our mission, our values and how we work together going forward, if we work collaboratively and choose to make the most of the opportunities ahead of us and if we empower our colleagues to express their preferences about how public involvement is best poured rather than have it served to them as it comes or refuse because they are not seen as members of the club. And I think we’re duty bound to think and act opportunistically and optimistically about the future however bleak we may feel at times.

How far we’ve come indeed and the dilemmas it raises was brought into sharp focus for me when I did some reviewing recently for a couple of the NIHR programmes, Invention for Innovation and the Health Care Technology Cooperatives and yes I really do, do some work occasionally. So, and this was just a few weeks ago, and this actually may have already happened to you but it was the first time it happened to me. It wasn’t that a number of applications included patients as co-investigators or co-applicants, or that many quoted INVOLVE’s guidelines and some had actually even read those guidelines which was rather good, nor that others went a bit overboard with some aspects of their PPI and advocated hundreds of focus groups to alter the design of a petri dish. I exaggerate a little bit but there’s some truth in perhaps putting an additional P sometimes in front of PPI which is around proportionality. And there was a moment where they presented this and I thought oh my goodness, this is like Fenton, we’ve set all these deer running with this dog that’s running around. No, it was actually that several of the teams who came along to present their application brought a patient or carer along with them to answer questions and this posed all sorts of dilemmas in my head. Excellent you might think, but at that moment I thought is this just simply about clever marketing, a new bit of game playing to tick the box? Are we being pitted against one another here? How do I ensure that their voice is being heard in the real way by my fellow members? How do I establish the sort of dialogue in such a short space of time available to me to establish that they feel generally part of the team and that we’re colleagues sharing the same enterprise?

Well, of course the answer to this dilemma as to many others we face in public involvement is that we have to turn to our values to guide us. And I’m indebted to Sally Crowe who drew my attention to this in a publication by Community Links which summed up the importance of values as follows: “Values are the beginning, they are what inspire us. Values are the means, they are what we do and how

we do it. Values are the end, they are what we strive to achieve.” And the fact is that we’ve got to return to our values time and time again, be honest with ourselves when we have failed to uphold them as well as applaud ourselves when we have. In 2007 INVOLVE set out how it approaches its work in the following statement, which you may have seen. But these are not values and now I think, given our growth and the external pressures we face, the time really does seem right to invite you to help crystallise a set of values that will guide us in the future. So following this Conference and as part of a survey that we will send to you, we’ll be asking you to help us identify what you think these values should be. And I’d hope that process as well as of course the outcome will be quite a unifying process for us to go through and something that you feel involved and can share very openly.

For me personally, and I know many other people have mentioned it over the last few days, one of the most important values to run through our veins is a commitment to work collaboratively with others. And I was very struck by some of the comments from researchers on the hot topics board which said we’re not all bad and I feel a little bit defensive, which is a little of what Alison was referring to. I firmly believe that we are not and we should never behave like the conqueror wishing to take over some fortress or build a new one. Rather we should, with others, strive to create a different space where research can happen, one that is much richer and more rewarding in meeting patient needs and priorities in the future and this spirit of partnership will be important in tackling some of the uncertainties ahead.

So let me set out what I think some of these challenges are and suggest some ways

forward. Well the first one is the changes sweeping across our health and social care system following the passage of the Health and Social Care Act earlier this year - some of you may have heard Jeremy Taylor from National Voices share his perspective yesterday. Now if you’re in the communications section in the Department of Health, and I say that as someone who’s a former communications person, you tend to see the world like this, which is not very clear probably up there but which is a graphic of what the new world or the new NHS looks like. I love the unbridled optimism of it and its neatness, although actually if you do study it, it’s quite a helpful graphic in many ways. And of course, depending on who you listen to about the NHS reforms you’re likely to come away with one of two pictures, much as we do when faced with an optical illusion. But let’s be honest, most of us feel that things look like this at the moment, don’t we, which is a Jackson Pollock painting called ‘Grey Silver’. But interestingly when Jackson Pollock was asked about his paintings he said: “My paintings do not have a centre, but depend on the same amount of interest throughout.” So perhaps our task is similar, to look at things in a different way to that which we are used to. It’s not so much about looking for the focal point as we once did, but identifying where and how we build and support networks to ensure the patient and public interest permeates it all.

I share the concern that public involvement is already a curate’s egg with places where it’s good and those where it is poor or non existent, that this may be amplified as the picture unfolds. But on the other hand, I think, statements by Malcolm Grant, who’s the Chair of the Commissioning Board, who was recently quoted as saying that patient experience is the Board’s most important concern, and others, give us license to roam and forage in ways that we could not have before. And the question really for us is where do we roam and what are we foraging for? What I’ve heard from many of you is a desire to use the current state of disruption, and it really is a state of disruption, to forge new alliances with our public involvement colleagues and others in service provision, for instance to map what’s happening in public involvement and to ensure public involvement is central to the workings of new structures. So we’re really talking about networks and linking up. Some of those such as the Academic Health Sciences Networks and Integrated Clinical Research Networks are going to be crucial in the new world as networks. And some of the work around that has already been taken forward by INVOLVE in various task and finish groups and identified as a priority for the future. We really do have to work much harder together, INVOLVE with you, at local and national level, to really get public involvement inserted into the governance and accountability of these new structures. And that’s going to probably be my top message from this Conference tomorrow at the Strategy Board.

Let me now turn to the issue of patient choice in research because one of the ironies actually of the Act is of course it’s very good from a research perspective or the

framework that it puts in place is very good in terms of a research perspective. There are now duties on all local NHS organisations to promote and advance research. Evidence, patient outcomes, quality are in the ascendency as drivers in the system or so we’re told, and patients will have new and improved levers to exercise their choice to take part in relevant and appropriate research. These include the NHS Choice Framework on Research and the revised NHS Constitution, and the aim of that is that research should be seen as an integrated part of a patient’s care and treatment. Again, therefore, I think the alliances that we build with our colleagues across service provision are going to be very important and very powerful in the future for that reason. Our priority at this point must therefore be to ensure that improving access to research is not interpreted solely as a recruitment drive for clinical trials and other studies, a bit like this which is actually from America. It needs to be defined in terms of patient outcomes and benefits. It needs to be based on shared decision making and knowledge exchange, information, evidence and tools at people’s disposal to make an informed choice, the stories of other people’s experience in research and of course the role of public involvement. Public involvement is going to be absolutely integral to delivering this agenda in a way which is as much shaped by, as it does match, patient preferences. In simpler terms it’s about moving things closer to the patient. But perhaps we also need to go through a bit of an attitudinal shift ourselves to make this a much more accessible part of what we do at times and think about the language and terminology we use and how that may also give an appearance of an industry as opposed to a movement.

Just to give a sense of what I mean about moving closer to the patient, I’m going to just show you two things about the UK Clinical Trials Gateway. So how many of you know about the UK Clinical Trails Gateway? Put your hands up. Excellent response. Far different from what it is in the wider world. So this, as you know, has been developed ostensibly under the Life Sciences Strategy to help patients find out about open clinical trails and therefore to assist their participation. And as some of you may know I’ve been working on a survey of patients and the public to find out what they think about this website, but also this downloadable app. That’s not been published yet and I just wanted to give you a sort of preview of the results because I think they’re very interesting and what they tell us about what people think of these. So the basic story here, and of course you’ll get these slides along with all the others from the Conference, is actually people think this is a great innovation. But it could be much better in terms of its content and quality and functionality and I think there are two other things which tell us about if it had involved the public earlier on then we may have had a better device than what we see at the moment. The first one I‘m going to point to is the fact that many people, you’ll see there 64% which is the first thing in bold, would like to find out about trials recruiting in their local area. Things are becoming more local for them in terms of health service provision. This just gives you a national picture and it doesn’t really assist you in helping to find and get access locally. The second one is that there was a very strong feedback from people that rather than being pointed back to their general practitioner, which is what the website says at the moment they should do, they wanted to actually make direct contact with the clinical trials sites without doing that. And there’s a very, very strong sense, I think, of empowerment coming through within and among patients about how they regard research, in a similar way we’ve seen to other places of health and social care provision, and we need to listen to that. So at the moment I’m drawing up the recommendations on that survey to go to the people who run the UK Clinical Trials Gateway. And I think we will see that develop quite significantly in a different way over the next 12 months, so that we do get it closer to what patients want. And an integral part of that is going to be the user panel that we’ve enlisted as part of the survey.

I’d also just like to very quickly say that it’s been really helpful to hear people’s feedback about the regulatory environment and how it stands for patients and the public because we’ve begun to forge a relationship with the new Health Research Authority and I think there’s a huge opportunity for us to collect your experience and your wisdom and present that to HRA and to begin to work on a new regulatory

environment that works much, much better for patients, whether in terms of what consent forms look like, or in terms of how research ethics committees are run. So I think this is a really, really important agenda and if you have any other insights that you’ve not been able to share with me or someone else now, please I do encourage you to email us or contact us about them because this is a very important point in the HRA’s development in terms of protecting and promoting the public interest, which is what its mission is about. The next one I wanted to come onto is patient data. Sorry, the other thing I was going to say was about going from a Ceefax sort of transmission type system to being a much more smart one, but that ‘smart’ also for me includes being accessible to wider patient groups and not just those that have online access or a mobile phone.

So the next thing I wanted to talk about was patient data and we’ve had a lot of discussion at this Conference about patient data, obviously beginning with Iain Chalmers. INVOLVE has long been involved in a debate and we’ve most recently given evidence to something called the Caldicott2 review on information governance and we’ll also be responding to the document that you can see up there which is the NHS Constitution. And in all our representations about this, whether they’ve been about access to medical records for research or the potential of ‘big data’ as its

often termed, INVOLVE has stressed the importance of putting the patient, first, most obviously in terms of security and confidentiality. But thinking ahead, and the task is now also one of articulating the additional or equivalent rights and expectations that should flow to the patient, being able to control their data in ways which will be familiar to them from other aspects of their online life like Facebook. Accessibility, of course, a commitment to support them to use data to help prevent ill health or manage their condition. And to access clinical trials and other data upon which that treatment or care is based, as Ben Goldacre has quite ably and brilliantly written about in his book. This is what I call the human face of big data as put on the cover of this book. The consultation on the NHS Constitution gives us an opportunity to set out what I think is the quid pro quo for patients around data.

But I also think the time has come, well in my opinion it’s well overdue if when you think that this article about the rights of the patient in clinical research was written in 1988 by Andrew Herxheimer, one of the founders of Healthtalkonline. The time is really right now I think to lay down the rights of patients in research, a charter which would set out some basic expectations on information, consent, dignity, respect and feedback from researchers. These are perennial issues we have long been concerned about but where the discussion and debate has meandered rather than coalesced, and I would hope that such a charter might give it a new centre of gravity and be an important tool and an empowerment tool for patients who are thinking about taking part in research of any sort. Given the global nature of research nowadays, and who cannot be affected by what we see in countries like India around clinical trials, I would hope that this is something that our partners and colleagues in other countries would work with us on, and with it develop a much firmer international partnership of public involvement organisations. And that whole international partnership arena is something that’s very much in my line of sight as Chair of INVOLVE in the coming years.

The last challenge I wanted to talk about was around funders. Some of you will be familiar with this chart that appeared in the joint publication by INVOLVE and the National Research Ethics Service published at the end of last year. The report was an analysis of the public involvement component to grant applications put before NRES. And the essential story to take from this is that the National Institute for Health Research funded applications were far better in terms of the public involvement component than those funded by charities, the NHS, industry or others. And we have been fortunate in the UK in that a sizable portion of the government’s health research budget rests with the one organisation, NIHR, that has embraced public involvement in research from its establishment in 2006 even though it’s got a long, long way to make it permeate everything. And as INVOLVE’s funder it’s also given us a very stable and sustainable base from which to work. But the further afield you look in terms of funders the more disappointing the picture becomes, and I continue to be somewhat dismayed, for instance, by the lack of movement by medical research charities around public involvement and I think it’s something that we need to really work on very hard in the coming years. But from our point of view that also means that we have to raise our game a little with how we engage with the making the compelling case for change which will make them sit up and take notice, whether they be charities or industry. So, remembering my own time as Chief Exec of the Association of Medical Research Charities, it was interesting when I was there to see how the influence that we had with government grew in tandem with our ability to tell and quantify our contribution to the overall enterprise.

Anyone reviewing the abstracts that you’ve seen in the Conference this week will see how seriously we take the business of impact, but we’re not perhaps thinking through enough about how to talk about those impacts and communicate those impacts so that they resonate most with the pre- occupations of our key audiences. And I think someone, very wisely saying during the Soapbox, pointed to the fact that universities are shortly to go through a Research Excellence Framework, 20% of which is around impact, and we should be using that as a very strong lever to begin to get people to understand how public involvement can help to deliver that.

So these are some of the frontiers in public involvement as I see them and you’ll have a chance to identify the priorities you think INVOLVE should take forward in the future in our follow up survey to the Conference that I’ve already mentioned. I’m also sure that there’s going to be many, many actors who play a part in this. We are a rich and diverse community and long may it remain so. Those who strike it out alone by necessity or choice and bring back messages of new things found or not, the wagon

trains of communities who will circle at regular points on their journey before settling in one place, the Evangelicals who are good at spreading the word, and the road or rail builders who begin to bind and grow the communities that set out ahead. Who can be in any doubt, for instance, about the perennial power of the personal story to shift people’s thinking and improve practice after this conference? Or when you read articles as powerful as this - a piece by Matilda Hale and Professor David Jones and others - published in the BMJ just a few weeks ago which is open access. It’s about having mutual respect for what each of us can do from our respective positions and their inherent limitations as well as opportunities, to know what each other is

doing and how it contributes to the whole. So I think some of you I hope will have gone away with a greater understanding about the particular position as an advisory group that INVOLVE holds. Our job is to agitate within the hive, your job is to agitate outside the hive. What we need to do is communicate between us to make sure that those two things work together.

So just two last concluding thoughts. One is about how we are organised. What we do need to consider as we grow is how we organise ourselves and come together in the future. It’s really clear that we are faced with some very strong development issues or growing pains in terms of capacity and capability, for instance the size of the community now being called upon to do ever more in the name of public involvement, the variability in public involvement, the skills and the learning and development that’s needed, the building of networks, the extent to which knowledge is shared between us. And we’re particularly taking a piece of work forward on learning and development as you will have heard and perhaps answered the questionnaire over the last two days. We in INVOLVE cannot do it alone. In fact we have to do it by working ever more closer with you and you working ever more closely with us if we’re to turn what is at the moment a community in this room into a much, much wider and more powerful movement. But nor should we be afraid of looking at new ways of working as we’ve already began to do in INVOLVE with our project groups. Thinking about that weekend trip I took to see the new James Bond movie and the thoughts it prompted in me about public involvement. As you’ll know James Bond is 50 years old this year and has been through many, many transformations but we still know it’s James Bond because of the recognisability of the values he stands for and his various trademarks and so it can be for us.

And therefore we return to our values. I was heartened when someone in the run up to this Conference said the INVOLVE Conference used to be the only place to come to and now it is the place to be. And as Chair you can imagine that’s music to my ears. That we’re able to provide a safe environment where people can share their personal stories and draw strength from others, where we can all pause and reflect on how we approach the future is something we need to hold onto. What did Abraham Lincoln say? “If I had eight hours to chop down a tree I’d spend six hours sharpening my axe.” And these occasions are such moments. He also said: “You cannot avoid the responsibility of tomorrow by evading it today.” Our values,

collaboration, rights and expectations, asking challenging questions, how we are organised, these are essential blocks in how we grow in strength as a movement and take the initiative today rather than being reactive, as someone has pointed out. For me, they are the means for arriving at a point where the choice in public involvement is not about whether it happens, but how it is best served to improve the quality of research so that it meets the needs of the public and patients. Mine is shaken with ice and a bit of lemon. What’s yours? Thank you very much for listening to me.

**Alison Faulkner**

Thank you very much Simon. Now, does anyone have any final questions or points that they’d like to put to Simon or to anyone else in INVOLVE, or to me even? Any final questions? I see lots of people …

**Simon Denegri**

… rushing for the bus …

**Alison Faulkner**

… gathering up their bags …

**Simon Denegri**

Quite rightly.

**Alison Faulkner**

… and coats and making for the exits, but any final questions or points that anyone would like to put? Yes. Is there a mic out there, does anyone have microphone available? Ah yes there’s somebody down at the front. Thank you.

**Audience member**

I was just wondering do we have to keep using the word ‘patient’ and making a distinction between ‘public’ and ‘patient’? Can’t we just use ‘people in research’ because frankly from my life I’m sick and tried of that role. And it doesn’t matter how many times I try to step out of it, it’s still seen just as a patient and I think it’s not, I’m a member of the public, I’m a person. And I think we should start by dropping that word actually, it has lots and lots of baggage. I don’t know why that is the medical model - calling people patients.

**Alison Faulkner**

I personally agree with you and I don’t know what Simon thinks but there’s such a diverse range of views about language, isn’t there, about what we want to call ourselves - service users is another term that many people don’t like. But we are all in it, we are all people members of the public.

**Simon Denegri**

Well, I think it goes back to what you said about identity, Alison. And I do absolutely accept the point. It’s very difficult to change these things when they’re so deeply held within the system, the way things are run, the way that attitudes … but I think you’re absolutely right.

**Audience member**

But you have to start somewhere. And that is just drop it and use, I don’t know, the word ‘people’ is perhaps a bit better. They make up the public.

**Alison Faulkner**

Yes, people in research is that website.

**Audience member**

That’s it, thank you.

**Alison Faulkner**

Any other questions from anybody? Oh yes, there’s one or two in the middle now coming up. Great.

**Audience member**

Well, just to say by the way, to the last person that we use personal and public involvement for PPI in Northern Ireland and that seems to do the trick. But this is my first INVOLVE conference and I found it very refreshing and very encouraging and as a mental health service user quite often you just think this is like pulling teeth and when did I sign up to be a dentist? But you need the perspective of saying, hey this is 16 years or 17 years since we began and this wouldn’t have happened 16 or

17 years ago, it wouldn’t have happened ten years ago in the same way and this is very encouraging. I’ve come for the first time and I hope to be lucky enough to come again.

**Simon Denegri**

Right that’s…

**Alison Faulkner**

That’s lovely.

**Simon Denegri**

…brilliant to hear. Sorry Alison.

**Alison Faulkner**

Thank you, sorry Simon, that’s really great to hear thank you. I think there was another one somewhere in the middle? Yes?

**Audience member**

Yes Simon, you were talking about a meeting that you are going to tomorrow and sorry I’ve forgotten exactly what that was, but you were saying that you were going to put some points there and I was just interested as being so much enthusiasm and commitment and provocative sort of questions and debate going on. And I’d like to just be reassured that that’s going to be taken forward into a wider arena. I mean we have a very wide arena here but there’s one thing I’ve taken from these last two days is that there’s a lot still to be done.

**Simon Denegri**

Yes, yes absolutely, so tomorrow we have our moment on the agenda where we will talk about the public involvement agenda. And so one of the key things that we’re going to do, me and Sarah, as part of that is feedback the issues from this meeting, and I think that’s very, very important, that we can come straight from a conference and say this is how our community feels, this is what’s not working, this is what needs to happen, these are some of the solutions because we’ve heard some fantastic, very simple solutions to issues this week. But that’s just one forum and the thing is that, like everything else at the moment, you’ve got to do it at the top and you’ve got to do it at the bottom and, and it will meet inbetween. So I encourage you to do the same thing when you go back and all of you because it’s very important that we do that.

**Alison Faulkner**

Any other points or questions?

**Simon Denegri**

There’s one down here.

**Alison Faulkner**

Okay there’s somebody down here yes.

**Audience member**

Thank you, I’ve found it very interesting. It’s about my third INVOLVE Conference. I work with adults with learning difficulties in Derbyshire and I think we are at a crossroads and I think we’re seen as a radical fringe still unfortunately. And I would reiterate my colleague’s comments here about putting people back into the equation

because of the patient agenda and GPs are going to be owning £80 billion of the budget from April. And they’ve set up a patient participation group which I’m on and a patient reference group which I’m on but it’s just exhausting because really all we’re doing is going around the same circle and some of the debates are very, very low key, whereas here we’re having interconnected debates. And although I don’t know enough people to get hugs and kisses I actually soak up the atmosphere and it feels warm and it feels cosy and it’s comfortable. But you know in the real world out there we’re facing huge challenges and changes and the disabled people’s movement is really going to be at the forefront of a lot of the cutbacks which haven’t yet gone through the system. And I’m really concerned that with their patient focus and with their GP looking at just the parochial because a lot of GPs will only be looking at their patch, but you’ve got to be careful that we don’t lose sight of this people-first movement. And we really do have to see it as a movement because I’m here representing marginal groups, people with learning difficulties who haven’t got the same voice or who don’t get the same respect in society and certainly don’t get the same share of the health budget. And there’s a real danger at the moment with the GP practices just looking at mental health and learning disabilities, shoving it altogether and calling it one thing and everybody’s going to suffer because of that re-definition, re-classification. I’m really concerned about the future and I don’t want to put a dampener on the Conference, I think it’s been really exciting, but I also think we’ve got to be careful, we can’t just be preaching to each other, we’ve got to get out there and really push this. So whatever we can do to change the language, because language is the most powerful tool, and that’s what we need to be doing.

**Simon Denegri**

And I think it also goes back to what I was saying about values for instance and why we need that set of values because that binds us together and gives us a common language to begin with. And then I think it’s also about links, linking up a network, so yes there’s this whole range of different mechanisms spawning and along with different models of so-called public involvement. And we have to really make things more linked up and more networked and support people now. You can’t do it all from within this space but we can each go and do our own thing to help that and if we’re unified by values it becomes a much easier process.

**Audience member (Derek Stewart)**

All clinical commissioning groups have a duty to inform people about what research is appropriate, as you said about the Constitution. If we do nothing else go back and look at what they’re doing and then ask all your Trusts how many people are taking part in research because that’s a good surrogate for looking at how they’re doing involvement. So it’s asking real targeted questions of those Clinical Commissioning Groups because if it’s not tied to service delivery then actually it makes no sense for me.

**Alison Faulkner**

I just really share those concerns. I think whenever there’s a massive change in the NHS, public involvement loses out - whatever we’re going to call it today ‘people’, ‘patients’. And I personally, I’ve been invited to go to my GP patient involvement group, and I think it’s exhausting, these changes are exhausting and I don’t want to go back to being a patient again for the purposes of the next movement, the next change. And we’re exhausted by the changes that are going on anyway in the disability field. I think it’s exhausting. Not wishing to finish on a negative note but what would be so helpful is if somebody knows of a resource where those questions that Derek has just mentioned, these nice targeted questions that we can use, we can find them and use them in our own local groups.

**Audience member (Derek Stewart)**

I’ll put it on my blog next week - the set of questions.

**Alison Faulkner**

Derek says he’ll put them on his blog next week, a set of questions that we can use to take to our Clinical Commissioning Groups.

**Audience member (Derek Stewart)**

And Simon will do a link to it.

**Alison Faulkner**

And Simon will do a link to it, brilliant thank you that’s fantastic.

**Simon Denegri**

Of course I will Derek.

**Alison Faulkner**

That’s very helpful because personally I’d love to have the resource, the knowledge to know what questions to ask. Any more points? Or are we ready on that quite helpful note to draw a close to the Conference? Final words from you Simon?

**Simon Denegri**

I just want to thank everybody. I think it’s been a fantastic two days and really, really interesting and inspiring so I wish you all a safe journey home and see you in two years, if not well before I hope.

**Alison Faulkner**

Thank you very much everybody.