



TRANSCRIPT

AAAGP Plenary: Driving change with research

Thursday 16 July 2009, 9.30am

Marie Pirotta:

Good morning everyone. My name is Marie Pirotta and I am here on behalf of Professor John Emery who is overseas at present and I want to extend to you all a very warm welcome on a chilly winter's morning here in Melbourne to the Australian Association for Academic General Practices plenary session on Driving Change through Research. We are going to have a very interesting 90 minutes and we will start with a speech from Professor Frank Sullivan and then we will be privileged to hear the winners of the distinguished paper awards. So let me start by introducing Professor Frank Sullivan. Frank is the Director of the Scottish School for Primary Care and he is the NHS Tayside Professor of Research & Development in General Practice and Primary Care at the University of Dundee. He is going to be speaking to us today about driving change in Scottish primary care and he is very well credentialed to do that as he has over 120 peer reviewed publications in this area. So please warmly welcome Professor Frank Sullivan.

Professor Frank Sullivan:

Research driving change in Scottish primary care

Thankyou for inviting me to come to Australia on this visiting fellowship. I am really pleased to have a chance to hear about some of the challenges that you are all facing and how you are going about to try and solve them. What I would like to do is share how some of the changes that we have made to the research enterprise in Scotland have started to make a bit of a difference to the way that health care is delivered. I am going to start off with a failure first of all. Twenty years ago the Chief Scientist Office in Scotland called for research into the management of leg ulcers in the community because it was then as it still is now a major problem and how many grant applications did they receive. None. Nobody thought they could do that research and the next twenty years we have geared things up and earlier this year we won the BMJ's research paper of the year. A bit of a history of how that happened, talk about SSPC the programs of research are, how the network works. I know there is an issue here about how primary care research networks might be configured. A bit about higher level training opportunities, some of our successes including the trial we won the prize for and some planned developments. For those of you who haven't been to Scotland it's the frozen bit at the North of the UK. Five million people, a bit over 1,000 practices and 40 community health partnerships, that's the organisations that encompass not just the GP's and the nurses but physios and interestingly for the past seven years now, social work departments as well all in the one organisation. I work in Dundee. After the debacle with leg ulcers John Howie undertook a report which said that what was needed was three essential characteristics in order for their to be successful research in the community and what happened to that official Government report? Same as always happens they lie in the shelf and no body bothers

with them and for a long time nothing happened. A decade later Sally Wake who addressed this conference a few years ago was an inaugural director for the Scottish School of Primary Care where we set things up in a more organised way and this time there was actually a strategy to try and deliver on that and where did we come up for the plan for it? We looked at various places in the world where there were research enterprises in primary care going on and the Dutch at that time and still and still now probably have the leading organisation and ability to deliver on doing research. I do have a bit of data comparing the UK and Australia if anyone wants to speak to me later. You are catching up but still between ourselves and The Netherlands. We looked at them and the key thing there was the idea of collaboration across the country where people who had the expertise and Amsterdam would students post docs referred from Maastricht's and they would say well we don't do that kind of work in Maastricht's but the guys in Amsterdam are really good at that so we thought that we would reconfigure ourselves on that much more collaborative way and that further developed the takeover in end of 2007. The first phase was building capacity for doing research and this time it was much more about doing the research, getting the programs. improving access and only delivering higher level training opportunities moving away from the lower level and the main groups are the ten universities in Scotland who do primary care research. Some of these are the ones with the medical schools as you would think like Aberdeen, Edinburgh and Glasgow. St Andrews is half a medical school mostly pre clinical but there are other ones that don't have any medical students at all, but they train lots of primary undergraduates and do continuing professional development and lots of specialities. One of the first things we did was to appoint some Chairs. We gave the universities we made successful bids funding to set up Chairs in Primary Care. We give them half the money and the university has to come up with the rest of the money. Glasgow successfully bid for one in co morbidity and Aberdeen and Edinburgh for one in cancer. The research is really pretty focussed and on very practical applied research. Scott Murray's group who has about 12 people working on palliative care in Edinburgh have developed these gold standards that some of you may have heard and the figures here show the level of adoption of these standards across the country in patients that are dying so the programs are very applied types of research and when the Chief Scientist just offered just under four million pounds for applied research programs last year, three and a half of the four bids were won by primary care. There were 37 applications from a whole bunch of public health and hospital specialists as well for doing applied research but Stuart Mercer, Bruce Guthie and Brian are all academic GP's and Christine Bond is a primary care pharmacist and she was co-applicant with Peter Helmes in Aberdeen. Again you can see these are all very applied research with things to try and drive change in the health service and make improvements and they have got significant funding. The network, what does it look like. It's configured across the country in these four nodes that the country is divided up in. Basically that is the network, a group of people who are on the ground in the nodes who are going in helping researchers get access to practices. Sometimes those researchers are GP's or other primary care workers and sometimes they are academics working in departments or they are secondary care people wanting access. Its part of overall UK research network where we would be one network in the same as the southwest England would be a network. Wales is greyed out but they have a very similar structure to Scotland where the School of Primary Care and the network is linked. That's what happens, the networks get the equivalent of 500K for support, infrastructure, they get a whole lot of practices typically in that range, although we had 600 practices engaged in different studies last year. In England they have a research practice scheme where practices are paid between two and fifty thousand dollars a year for engaging in research. These ones might only give access to their lists for one study. These ones would be doing a lot more hands on work and three or four studies and they are expected to take part in the National Portfolio of Research. There is also other networks, those of you who know the UK that the whole research enterprise is being configured on these networks to get infrastructure support and these are examples of three of the other Scottish ones and some of the research that we work with them on. We know a lot about the practices because we are visiting them all the time and there are members and we have got a lot of data. If our researcher wants to

find twenty practices with a range of characteristics we can help find that from a list of 40 or 50. We have got good access to GP records for finding prevalent conditions where we can get aggregate data from either centrally Information Services Division in Edinburgh and HIC is the building that I work in, the Health Informatics Centre where we can find 5,000 people with a recent diagnosis of Parkinson's Disease or 17 children with Prader Willi Syndrome and contact the practices with the patients that we are interested in the practices write to the patients to see if they are interested in the study. Practices are quite keen on that but they would rather we did it all and it was all done centrally in a blended email merge and they would just look at the screen and see who the patients were. We are not doing this yet because again there are problems with consent and access to records which are unique to Scotland. We are also working on a new recruitment tool so lots of studies in primary care, its not prevalent conditions you want, but rather you want to be getting people as they present within 24-48 hours and we have developed this multi agent system that spots patients, in this case its a pharmo genetic study looking at response to oral hyperglycaemic agents when they are first prescribed. We also use surveys about deciding on studies after a complete disaster we had of a trial that wanted to recruit patients to either laxatives or lifestyle advice for chronic constipation which took up about three years of man hours in trying to recruit practices and got no participants. We decided that after that we would find out if the practices want to do the study in the first place so this is one we are working on at the moment thinking of doing a study of trying to prevent post operatic neuralgia so that's how the networks all configured. Once we get started with studies we have contributed to some of this methodological development from Aberdeen about trying to treat projects as much more an industrial issue and not flying by the seat of your pants that whenever you get a study that you go through all the issues about building the brand values, planning your marketing, selling it to the practices and the patients and then carrying on the engagement right through so a lot of the network is done by trying to manage the studies to make sure they are really successful because the continued funding of the network depends on the studies being successful. We are just gradually increasing the studies last year it was 57 with a spread of local and national studies being undertaken. Higher level training opportunities. This is one of Chris Del Mar's ideas along with Paul Glasziou when they were in Brisbane that some of you have benefitted. We have people going initially meeting in Oxford to try and get post docs working together and sharing their ideas across the world. Some higher level political things trying to get sufficient training posts, this is a report we just published two weeks ago. Another thing the School has done is to try and emulate what Manchester has done with Barbara Starfield. Manchester is probably the top research group in the UK had no papers in the New England Journal of Medicine for the first fifteen years of their existence and then they got Barbara to come as a visiting professor and crucially they appointed a research fellow in Manchester who worked for Barbara and she engaged with them to the extent that they already have four with the fifth on the way and she is saying this is the aspect of your work that they guys in New England would be interested in and if you are analysing the data this is the way they want to read about it so we are going to be using that kind of model and trying to persuade them and some of the best professors in primary care in the world to come and do that kind of model with us. Some of them are in this room. I was going to use Bell's palsy as a specific exemplar of how we were able to deliver when we couldn't with the leg ulcers so this was an idea I had about twelve years ago when I saw someone with Bell's palsy and I wasn't sure to do about them so I looked up the Cochrane reviews and the various bits of evidence and I realised that there wasn't any good evidence at that point which was in the mid 90's so I spoke to the MRC ENT research unit which happened to be in Glasgow where I was working at the time and came up with a brilliant research design and of course it was completely refused. We tried six or seven times, nobody would fund it and then in 2001 there were two more Cochrane reviews saying we still don't know how to treat Bell's palsy and the Health Technology Assessment Board called as a competition and they offered 2/3rd's of a million pounds to try and answer the question so this time we applied and we got the money and after quite a bit of effort we managed to get recruited to target, they key thing was getting to the patients within 48 hours so that's why the question had

been around for forty years because all the previous studies had mostly been in hospital but primary care we can get to the patient and other conditions a lot faster. We had the problems right at the beginning with recruitment, we were starting to sweat a bit and we called on celebrities who had offered to help with recruitment. People who had had Bell's palsy and recovered. Unfortunately George Clooney was not available but Graham Garden was and he was very helpful and he made several radio appeals to patients and to GPs to refer patients so we got our numbers. We needed to have 480 patients complete and 120 in each of the groups and we managed to keep it all balanced and get through that OK and that was the results. We broke the code and I just thought I have never sent anything to the New England Journal of Medicine before and I thought why not, this is one that could bare a useful answer. They only asked for 37 corrections to the manuscript and the analysis but they did take it and that's what we won the prize for at the BMJ which was surprising. Some of the newer stuff on making advantage of what we have in Scotland would be our ability to do record linkage with patients that are on the single health system in Scotland. There are two private practices who are not part of the health service in Scotland and all the hospitals apart from three or four are part of the health service so we can get data and the first example of using it was a diabetes system in Tayside. It's now gone national across Scotland, data is shared between all practices and hospitals and anybody who is responsible for the patient can see data from wherever they happen to be and this is all the GP systems. You can use any GP system you like in Scotland but you will only get paid for the ones that share the data with other people. The CHNo is mainly used to link all of that together, a single ten digit identifier and we use that in quite a lot of our research. We have got a big grant recently to try and extend it into other systems, not just in primary care, including all the aggregate administrative data on cancer registries and hospital admissions etc. A whole range of activities about trying to make sure what we are doing is approved by the public and lawyers and researchers can use it and a series of exemplar studies trials like I have already talked about epidemiology both observational and pharmacoepidemiology, pharmacovigilant studies and some work with health geographers as well. Lots of people are interested to get access to the primary care data and we have just got some more funding with Brendan Delaney who is in the English School of Primary Care leading on work which has got quite a lot of importance for primary care research. This is all about primary care research, linking primary care data and some research data sets that we are going to be working on and the health services is very keen and will set up by the end of these two projects in three or four years time, virtual micro data laboratories where across Scotland any researcher or health service manager if they have got the permissions can go and look at the data at patient specific level. The last slide is saying we have made a difference to climate infrastructure and skills, we are still not good as the Dutch because they been moving ahead just as fast as we try and catch up with them but we are getting there and there are still things that you are doing that are better than what we are doing but I hope that some of what I have said today will be of interest and I am happy to take questions. Thankyou very much.

Questions:

John Wakerman, Centre for Remote Health

Great story Frank. Good to hear. Yesterday there was a bit of discussion about impact and the impact of the sort of research that you are doing. Can you talk a bit about the impact of your research on practice and how you are measuring that?

I was chatting about this yesterday evening. It depends who you are speaking about. In terms of the way the Universities look at it, they are only interested in the number of citations of your papers. They don't really care about anything else. But as probably the case here at lot of the funders are uninterested in the impact of your research and will insist on novel measures being generated like incorporation into guidelines use by patient groups and designing their materials and getting the evidence put into knowledge management systems so the Bell's palsy example now

there is a thing called NHS evidence and there is a brief summary of that and then some interactive clinical decisions. At the moment we are not collecting that in a systematic way but you can present it and we need to say the funding for the primary care research network we would meet the funders, chief scientist office and the health boards twice a year and tell them about this broader range of things that we are doing and try to disseminate good practice. It's a big issue for people all over Scotland and in the rural peripheral areas. It's fairly wide spread. If we run a seminar on that they can see that we are solving health service problems.

Teng Liaw

Thanks for your presentation and sharing your experiences. From what you say the Ch number seems to be a key thing in setting up a research network. Australia is in the processes of introducing a unique health identifying and I was just wondering if you have got some words of wisdom in terms of how we might leverage off your work and use the impending availability of a health identifier?

We can use this for a short commercial break that Doug Boyle and I are running our session after the tea break. For a long time we had both deterministic linkage and also problealistic linkage method using a thing call Sendex where similar sending things were linked together and it's not as effective. The history goes back to 1978 of the introduction of this ten digit identifier so we are 30 years on before its in universal use. So be ambitious in your planning but be realistic in the speed at which they are going to be realised and like most diffusions of innovation go for the people who work with you. First of all the innovators and doctors, don't try and force the laggards to do something that they don't want to do because you need to have consent from a whole lot of people before you can do this kind of thing. You can't just impose it.

Nic Zwar, University of NSW

Frank, I think it would be fair to say we are quite envious of the research network structures you have in the UK, Scotland and also in England and in the Netherlands. I wonder how far you have got in terms of involving allied health and nursing in those networks. The studies you have talked about are largely general practice based?

In Scotland we have been multi professional multi disciplinary from the word go. Because we are five million people and I would say that the members of our network, the SPCRN, its probably half and half, half are GP's and half are other groups and that's under representation particularly if you think the number of practice nurses is probably four times the number of GP's. We also include dentists as well in our network. They tend to be very hands on in doing things compared to the GP's who think about problems and write things and rearrange systems, the dentists are rolling their sleeves up and straight away and designing a new kit.

Marzin Ghafel from Auckland NZ

The privacy and confidentiality is a big issue. I can see from your presentation that you can identify people and call them. It never happened in NZ we can't do that so how do you manage? The only person who can call them is someone who has got clinical responsibility for them.

We still can't do that in NZ because you are using the data from something different from the collection.

That would be normal whenever a practice is deciding to reorganise its diabetic services they interrogate the database on the number of diabetics and how many of them haven't been to have their feet checked. That wasn't the reason why they collected the data during the consultations. So it's just skilling it up. People call it secondary uses of data but I think improving the service and doing research in order to a future point make recommendations to improve the service is primary use of the data and most surveys are astonished we are not already doing that.

Jane Gunn

Thanks Frank. I think the other thing we are envious of is the Scottish School of Primary Care and the collaboration between the different Universities and I wonder if you could just say a little bit about that, about how well its working and tips for how we might do that better here?

There was already quite a strong tradition of people working together but it was the realisation that we could all differentiate and work a bit like the Dutch had done, so that if someone is interested in palliative care and comes to me, well we don't really do that in Dundee but Edinburgh is a bit over an hour away and they can be linking up with Scotts group. Somebody interested in pain management should be speaking to Blair Smith, so it was starting to work together and that made us serious players. Getting onto these post genomic studies biobank Scottish Family Health Study, if we weren't working together across Scotland we wouldn't have even been asked to do that. The hospital guys would just try to do it themselves, and not very satisfactory whereas because we are coherent group across the country we will say Cathy Jackson at St Andrews is the primary care lead on that bit of work. David Weller has the lead on cancer in UK not even Scottish level. The key thing was persuading the leading university to throw their hat in with the others which was Aberdeen at the time when we were reformatting in 2007. They were the strongest group and there was no advantage to them to say sharing with a group like Glasgow Caledonian, were a very weak primary care research group so persuading the strongest guys was actually like themselves interest to work together was the key thing and we all got on well together, with a bit of rivalry at some times but you have to keep sharp so when applying for the Bells palsy we weren't competing against other Scottish groups we were applying against twelve other English groups but we were stronger because we were the four Scottish universities applying for that grant.

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