# Role of Primary Care and the RACGP in Clinical Trials

## Slide 1

Hello, I’m Michael Tam. I’m a GP academic and undertake research and evaluation, medical education, and clinical work.

I am not Associate Professor Charlotte Hespe who unfortunately cannot be here today. I’m very pleased to have had the opportunity to delivery this talk on her behalf.

I’m a staff specialist at the Academic Primary and Integrated Care Unit of the South Western Sydney Local Health District and Ingham Institute, and am one of the conjoint senior lecturers of the School of Public Health and Community Medicine at UNSW Sydney. I think that this gives me an interesting perspective as although I am a specialist GP and have worked for many years in private general practice, I am also an NSW Health employee in one of the local health districts.

## Slide 2 – ecology

The role of primary care in research and clinical trials is immense and under-recognised. As such, it’s excellent that we are having this meeting to discuss how to move forward.

With how the Australian health system is structured, it is always worthwhile being reminded of the ecology of medical care. This data is old and from the US but remains just as relevant now. These are monthly prevalence figures for adults. In a month, 1 in 4 will have seen their GP. Perhaps 1 in 100 will attend an ED or an outpatient service. Only around 1 in a 1000 will have been admitted to a tertiary hospital. Now obviously acute care and hospital services are very important. I don’t think anyone questions that. That said, as someone who also works within the hospital sector, I think that it is easy to forget that the medical care that occurs within its walls are by uncommon events in the lives of most people in the community.

By volume, almost all medical care occurs in general practice. I’ll add, of course, that most health care activities are not through medical practitioners at all, but by people for themselves, and through their carers.

General practice is the coalface of medicine. The fruits of research and clinical trials – usable scientific evidence – if evidence and guidelines are to be implemented and used in medical care, it is in primary care where it will conceivably do the most good.

## Slide 3 – ecology

This is especially critical as it has been long recognised that there exists an “inverse care law” in medical care, and this is no different in research and research funding. Most health funding, and most clinical research funding, does not occur in primary care.

This does cause a problem. As a reflection, many and possibly most clinical guidelines are prepared by non-GPs, using non-primary care research findings, often of patient participants who don’t look a lot like my patients in primary care. Patients in real-life general practice tend to be more multimorbid – that is, having multiple interacting conditions – and just more complex in general – the psychological and socioeconomic factors to health and wellbeing.

## Slide 4 – grassroots

One of the perspectives that I hear not uncommonly is that it is difficult to recruit GPs into studies. As someone who does research in primary and integrated care, yes, recruitment can be difficult and challenging. However, there is often a subtext that is implied in these comments. Typically, some version of that:

* GPs aren’t engaged in research
* GPs have an obligation to participate in research
* Or that GPs should be “made” to participate in research
* … especially important research like mine!

And sometimes, it is explicitly said rather than just implied.

However, what are the perspectives of grassroot GPs towards research? I trained and have worked in general practice, but I haven’t worked in what would be described as a typical context for some time.

So, I asked!

On Monday, two days ago, I asked two social networks of GPs, their perspectives, stories, and experiences of clinical trials and research in their practices. The first is a Whatsapp group of Australian GPs interested in, undertaking, or who have recently completed PhDs. The second is a very large Facebook group of Australian and New Zealand GPs – currently with just over 6,500 authenticated members.

Over 24 hours, there were about 60 comments, which I have used to inform and ground this presentation. I have received permission from all individuals who I quote.

## Slide 5 – GPs are inundated with research requests

Firstly, GPs are inundated with research requests. I too receive these frequently. There is probably not a week that goes by where I don’t receive a request or two to participate in something. The second quotation is from one of the moderators of the Facebook group – they receive so many requests to promote projects that they have had to set up a set policy with defined criteria lest the group is “spammed” by these requests.

## Slide 6 – GPs asked to take on the costs of research

Quite a few GPs noted that they were effectively being asked to do work, often with a significant burden, without any recognition of the costs. I’ve seen this in the designs of many projects. I recall having a conversation with one of the research officers at our Unit, who reflected their exasperation with trying to explain to a non-GP specialty research team how mail works in general practice. The plan was to ask the practice to send out invitation letters to some 500 prospective patients, without any apparent recognition that this was asking each practice to donate around $700 to the project. Stamps and envelops cost money!

I imagine that most of us are paid to be here at this workshop? A GP who attends a research meeting during working hours is basically paying to attend.

## Slide 7 – reprise

This quote is from the same GP. It is important to recognise and appreciate that when GPs do participate in trials, especially those which are of some complexity, they do so knowing the costs. They are agreeing out of goodwill, and for the potential benefit of their patients.

## Slide 8 – competition

GP researchers do find it challenging when well-funded non-GP specialists do research in primary care. Separate to the issue of competition, there are issues about whether the researchers understand primary care and its context. Now I know that this workshop has a focus on clinical trials, which I imagine will see randomised trials as the gold standard. These are of course, very important. However, from the general practice perspective, and as I work in an integrated care unit, the integrated care perspective, randomised trials provide empirical data that can be quite incomplete for understanding complex interventions.

This is of course an opportunity – GP and primary care researchers should be included into trial and evaluation design on the basis the merit of the research design alone.

## Slide 9 – weariness

Put together, the GPs seemed to describe a lived experience of a certain weariness. A fatigue from disempowering circumstances and discourses. It’s important to understand that general practice is under significant financial pressure and most practices run quite lean. They are organisations optimised to running in their local contexts, for a mission that might not include research as a priority. Some GPs described the pragmatic decision-making processes and most had some similarities from an operational perspective:

* Will the project fit into the workflow of our practice, i.e., not interrupt our core business which is to provide patient care?
* Is it of likely benefit for our patient population, our staff, and/or our community?
* Is there remuneration that will cover the cost of resources, including staff time, required to participate in the study?

## Slide 10 – interpretation

It is easy to slip into a “deficits@ framework of thinking. What I mean is approaching the issue primarily by identifying what is missing or “wrong” with GPs and then trying to “fix” them. For instance, a primary strategy of aiming to identify deficits in knowledge, deficits in attitude, or deficits in time. And then trying to “fix” the knowledge with education, attitude with standards, and time with role substitution. This apparently simple approach will almost certainly not result in effective change. It is too narrow and decontextualized.

Now, this isn’t to say that education, standards, and improving resourcing aren’t important factors – of course they are! But, applied in the wrong manner, using a non-collaborative and non-inclusive stance will lead to disengagement.

Rather, at a high level, strategies to improve engagement with general practice need to be based on quality relationships. GPs need to be engaged with in a respectful manner. Research needs to be done with us, rather than about us or on us. GPs aren’t simply being a mechanism of patient access and recruitment.

These relationships need to be trustworthy. As a concrete example, we personally feel responsible for the data in our record systems – one GP describing it as the “sanctity” of the data. We feel very uncomfortable with the notion that an unknown external researcher will come to simply “extract” the data. It’s not just data – they are our patients!

And reciprocity – that there is fairness in enterprise of research. Relationship building is key. To be frank, most research projects probably cannot afford my commercial hourly fee – for instance, what I would charge for an insurance report. For research to work, it necessarily requires the altruism of the participants and this needs to be acknowledged and honoured. Reciprocity isn’t only in money and payments. Giving back also includes building research capacity in primary care, including and listening to GP researchers seriously in research design, sharing and communicating back results to practices.

This post from a rural GP on Twitter a couple of days ago encapsulates some of this frustration well. This was in the context of having received several research requests from non-GP specialists wanting to study what GPs knew to educate them. It is curious that general practice is one of those few specialities of medicine where someone who has never worked in that context will claim expertise in what GPs do, what they should be doing, and how they should do it.

## Slide 11 – role of the RACGP

I cannot speak directly for the role of the Royal Australian College of General Practitioners though I can convey the message from Associate Professor Hespe, the Chair of the RACGP Board, and Chair of the NSW and ACT Faculty Council.

The College is working with the MRFF to increase funding for primary care based research, and also with the Department of Health and AAAPC, the Australasian Association for Academic Primary Care, to strengthen GP practice-based research networks.

The College naturally encourages a collaborative approach with primary care researchers and PBRNs.

## Slide 12 – role of the RACGP

Charlotte says,

“In turn we are more than happy to assist in ways to communicate with GPs in general and to facilitate recruitment of appropriate patients from the GP setting.”

“It needs to be a win-win for everyone.”

## Slide 13 – synthesis

Putting it all together.

Remember the ecology of medical care. Almost all medical care occurs in primary care. Evidence generation in primary care settings is vital.

It’s important to appreciate the context of primary care and general practice, especially when it comes to research and recruitment. GPs are inundated with research requests that often expect them to bear the cost of participation.

Strategies to improve engagement require the building of quality relationships, based on respect, trustworthiness, and reciprocity. These need to be lived values.

And lastly, the RACGP is highly supportive of a collaborative approach and happy to assist, within that context. It needs to be win-win for everyone.

Thank you!