

APON Interest Group	Research and MRFF		
Webinar 1 date	20 February 2020		
In attendance	Marline	Squance	Autoimmune Resource & Research Centre
	Chris	Walker	Parenteral Nutrition Down Under Inc.
	Kristina	Elvidge	Sanfilippo Children's Foundation
	Megan	Donnell	Sanfilippo Children's Foundation
	Meredith	Cummins	NeuroEndocrine Cancer Australia
	Sean	Murray	Mito Foundation
	Monica	Ferrie	Genetic Support Network of Victoria
	Kate	Wakelin	NeuroEndocrine Cancer Australia
	Wendy	Bruce	Fragile X Association of Australia
	Heidi	Nicholl	Emerge Australia
	Joanne	Campbell	Metabolic Disorders Association Australia
	Wayne	Messenger	Crohn's and Colitis Australia
	Laura	Birks	MND Australia
	Gethin	Thomas	MND Australia

Apologies	Shirley	Baxter	Cancer Voices NSW
	Melanie	Funk	Hands to Hold Ltd
	Nettie	Burke	Cystic Fibrosis Australia
	Emma	Thompson	Arthritis Queensland
	Caroline	Zoers	Australasian College of Dermatologists

Facilitator Sue Carrick, Research Strategist

Observer(s) Catherine Holliday, Centre for Community-Driven Research

Introduction and purpose	<p>This interest group will work to develop a common platform for patient engagement in research and a research agenda for patient organisations to work towards. It doesn't mean that each organisation can't have their own priorities, it just means that we will look at what organisations are advocating for and see whether there is room for a common agenda.</p> <p>There will be three interest group meetings that will be designed to build momentum towards the APON 2020 annual meeting in Melbourne (15-16 June). At the APON conference, you will use have two options to choose from and we'll make that decision together closer to the conference. Option A: To design a complete system to ensure a patient-driven research system across the pillars of a) Prioritisation b) Engagement and c) Research Impact. Option B: To develop a collective research priority program to submit through existing NHMRC and MRFF mechanisms.</p>
Consultation question 1	The facilitator explained that the intention of the first part of the webinar was to understand how organisations are engaging in research, whether it is doing research, funding research or advocating for research.
APON member feedback	There were a few main areas that organisations had been involved with in research including:

- Priority setting
- Quality of care and health system research
- Funding research, and
- Supporting clinical trials (including funding and access to trials)

Some challenges were noted in relation to community engagement in research and there were some different perspectives on this.

A number of organisations noted challenges with staff being listed as ‘consumers’ on research applications. Even when great efforts had been made to implement procedures early in the process, there was still evidence of tokenistic or ‘tick-a-box’ consumer engagement:

“We had seven applications but what we were finding was people who had just put our organisation on that.”

Others organisations found they had very little active engagement from researchers and would like to be contacted for input. This was the case for groups where the research in their disease area was primarily at the basic research end of the translational spectrum, and they looked forward to the day when they can have more input.

One organisation noted challenges with being approached to support research recruitment, but researchers not being prepared with adequate information, including not having ethics.

There were some comments made in relation to prioritisation where some organisations had gone out to members to see what their priorities were, but found the results are sometimes not achievable, for example priorities might be out of budget or might not be realistic for where the research is at for the disease area (i.e. if what is needed is basic research to understand the mechanism of disease, there might not be opportunities for trials).

Other groups spoke about supporting clinicians and acting as a linkage point for clinical trials or providing information to their community when trials become available.

There were many innovative ideas noted by some of the organisations present who looked for existing mechanisms, for example consumer networks and registries to develop ‘push notifications’ about clinical trials. NeuroEndocrine Cancer Australia group spoke about a great initiative using an app linked to a registry that is used for clinical trial alerts:

“It’s also going to be a push alert for any clinical trials the patient might actually be applicable that they could be recruited into, as well as quality of life studies around the various hospitals. There’s also a study that we’re about to launch and launch into is getting results and making sure that we’re finding out that patients are getting their results in an appropriate manner and appropriate time frame, because there’s, as we all know, diversity as far as clinicians. Somebody might get their results the next day, somebody might have to wait three months before they actually get their results through, so we’re trying to fine tune and get an even platform for that”

There were some groups who had telehealth nurses through the Patient Pathways program who noted that this initiative may also have potential in the context of

	collecting clinical registry-type data, and this was filling a gap in their regular internal capacity to understand their patient population.
Consultation question 2	The facilitator asked about APON members views on collaborative research or co-funding research across common areas.
APON member feedback	<p>Most of the organisations had been involved in and/or were supportive of collaboration. Some spoke about taking the approach of identifying the world leaders, whether in Australia or overseas, and collaborating with organisations in that way. This was partly to avoid duplication and partly because of sometimes having limited expertise in Australia.</p> <p>Two groups spoke about supporting collaboration, but also being part of alliances that had good intentions but did not result in any outcomes.</p> <p>“There wasn't an autoimmune alliance that came together several years ago. We did a little bit of work, preliminary work around, concept of getting together to raise their agenda across those common immune diseases. That's not progressed recently anyway.”</p> <p>“That was part of the priorities of that, is to get some priority areas across and forming a network of people that are in the autoimmune, immune diseases group. We only had a couple of meetings and then there was a lot of background work that was done by MS, who was taking the lead role in this. I don't think we've heard anything since then. From our perspective, I probably have a different situation, is that I'm often approached by other not-for-profits to do research on their behalf, or to join with them to do that.”</p> <p>There was general consensus that there is an opportunity to investigate common areas of interest across the APON membership, including common processes for community engagement and prioritisation methods.</p> <p>“I think it's definitely worth trying to identify whether there's common areas and then whether we should go ahead from day one will depend on what we identified.”</p> <p>“It sounds good to me. I think the common area might be that we all want meaningful consumer inputs.”</p> <p>“I agree 100%. I think we should get some common areas in the national level, for sure.”</p> <p>“I think I'm more than happy to try and identify areas where we have commonalities. I'm hoping comparison of documents always helps, priorities, et cetera.”</p>
Observations and action items for CCDR	<p>Observation 1: CCDR's observation is that something that would be really useful on a national level would be about what community engagement actually looks like for research and what does engaging in a meaningful way involve. This also means articulating when a research project just does not meet the needs of patients and being able to work with researchers to align priorities.</p> <p>Action 1: CCDR will have a look at what guidance is already out there in relation to patient and consumer engagement in research. If there isn't anything that's useful for us as patient organisations, then we can absolutely generate something.</p>

	<p>Observation 2: A number of organisations have conducted or would like to conduct prioritisation processes. This is something that could be done as routine data collection.</p> <p>Action 2: In CCDR's Personal Experience, Expectations and Knowledge (PEEK) program, we can think about a few questions around research prioritisation that come from patients so that we're collecting data all the time about what patients are expecting from the research coming through in the different disease areas.</p> <p>Observation 3: There also seems to be a lot of different organisations that have an existing research strategy.</p> <p>Action 3: If funding can be found (as this is a larger project) CCDR could have a look at the strategies that exist and create a matrix to see where there are commonalities and where there are unique aspects. That will give us oversight as to whether there is the possibility to have sort of some common areas of prioritisation.</p> <p>Finally, CCDR would be able to do some case studies where people have had good co-funding collaborations to just start to collect that information and evidence around what does good collaboration for co-funding. That might be around even just using each other's review processes or things like that.</p>
<p>Update from CCDR</p>	<p>A resource that CCDR have already created are some information sheets about the health system and different types of research, basic research, epidemiology, clinical trials and so on. Organisations can access them on our website and they can be useful just to help educate patients that want to be involved in research. They are in Word format and can be downloaded them, adapted as you want, even put your own logo on them for your own use.</p>