APON Interest Group	Access to medicines, devices and health services		
Webinar 1 date	18 February 2020		
In attendance	Monica	Ferrie	Genetic Support Network of Victoria
	Melanie	Funk	Hands to Hold Ltd
	Chris	Walker	Parenteral Nutrition Down Under Inc.
	Kristina	Elvidge	Sanfilippo Children's Foundation
	Megan	Donnell	Sanfilippo Children's Foundation
	Meredith	Cummins	The Unicorn Foundation
	Michele	Hemmings	Mito Foundation
	Toni	Catton	Mito Foundation
	Piper	Marsh	Muscular Dystrophy WA
	Kate	Wakelin	NeuroEndocrine Cancer Australia
	Wendy	Bruce	Fragile X Association of Australia
	Hariklia	Nguyen	Dystonia Advocate
	Caroline	Zoers	Australasian College of Dermatologists
	Mariam	Zahid	Australasian College of Dermatologists
	Joanne	Campbell	Metabolic Disorders Association Australia
	Wayne	Messenger	Crohn's and Colitis Australia
Apologies	Shirley	Baxter	Cancer Voices NSW
	Nettie	Burke	Cystic Fibrosis Australia
	Hannah	Heather	Pink Hope
	Christine	Cockburn	Rare Cancers Australia
Facilitator	Mike Smith, Australian Reimbursement Expert Advisory Panel (REAP)		
Observer(s)	Catherine Holliday, Centre for Community-Driven Research		

Introduction and purpose	This interest group will work to ensure that patient engagement in decisions about access to medicines and health services (through the Pharmaceutical Benefits Advisory Committee (PBAC), Medical Services Advisory Committee, Prosthesis List Advisory Committee (PLAC) and their related sub-committees) remains in the community, is driven by the community, and leverages the systems and initiatives that APON members have established or plan to establish in the future. This is really important because there have been a number of initiatives in the past years – driven by the government or industry – and it's really important that we take a beat here to critically think about the direction that the community wants to take in the context of health technology assessment (HTA). 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, we will use that time to think about how APON members want the process of patient and community feedback to work and what does that look like? At the APON 2020 annual meeting, we will take a step back from the systems that are sometimes imposed on us as patient organisations and design a community-based system that works for us, giving patients the space to provide insights in a supportive environment, at a time that suits them and the freedom to talk about what they need to talk about.
Consultation question 1	The facilitator explained that the intention of the first part of the webinar was to review how initiatives that aim to increase community participation in decisions about health technology assessment have affected their organisations and get a

	sense of what APON members think the direction that their own patient populations want to take in terms of community engagement in the decisions around access to medicines, devices and health services (Health Technology Assessment, HTA). The facilitator went around the group to see what APON members present have been involved with, and their impression of that involvement. Did it work for them? Did it resonate with their members? Did something come out of it that was practical and achievable? Some examples of initiatives were provided including the Consumer Consultative Committee, the National Medicines Policy Review, the Patient Voice Initiative Conferences, and the Canberra Health Summit funded by Roche.
APON member feedback	There is a lot of discussion going on, but few practical outcomes for patient organisations and their communities. Members understood that change, particularly in policy, takes time however felt now is the time for some action and that this can and should be driven by the patient organisations. APON members representing rare diseases or diseases that do not have many or any therapies available were concerned that there were no opportunities to proactively engage in the process and that this would lead to a situation where they were needing to be responsive (rather than proactive) and that the system might not meet the needs of their patient populations. “Unfortunately, we haven't been involved in any access, consultations yet because there are no proven therapies yet. There are clinical trials ongoing and progressing, so we want to be ready when the time comes.” “A little like other organizations, we want to be ready if this particular product gets passed the FDA, and we need to take a look at it for Australia. There are no proven treatments for us. It's not fatal, but if there is something out there that can be of assistance, we want to make sure that it's accessible to families as quickly as possible and at a price point that is feasible.” There was a general disappointment from APON members that they had not been provided with opportunities to engage in some of the consultations and initiatives that had occurred. This prompted an important question of ‘Who gets to be involved and whose voice is being heard?’ There was general consensus that there should be mechanisms for organisations to contribute or play a role even in the absence of a therapeutic as they will (ideally) still be users of those systems in the future and are currently users of parts of the HTA process through access to diagnostics and health services (for example). Some examples were shared about how organisations had been involved or were preparing for engagement in HTA processes. One organisation spoke about providing submissions to the Pharmaceutical Benefits Advisory Committee (PBAC). They noted that it was valuable to be able to present the patient point of view in realtion to quality of life, but also noted that it has been a very reactive process. Another organisation spoke about looking to the future and have a focus at the moment on clinical trials and making sure patients can access trials. They also noted the importance of patient organisations in advocating for access to trials amidst challenges with local and national ‘politics’. A second organisaiton also spoke about a focus on clinical trials, working to attract international trials to Australia and

	accelerate/be prepared for clinical trials. An organisation that has quite a few therapeutic options available and many coming through the pipeline spoke about submissions they had provided through both the PBAC and the Medical Services Advosory Committee (MSAC). It was noted these were often clinician-led submissions and that there were challenges within their organisational capacity to collect and collate feedback to provide balanced and informed submissions. Organisations were asked whether they felt submissions that they had made were influential. The general consensus was 'We don't know'.
Consultation question 2	The facilitator asked about the challenges that exist for APON members and their patient populations, particularly in relation being able to be part of or engaged with decisions about access.
APON member feedback	Oganisiations spoke about the challenge of not being invited to participate or not reasonably knowing what opportunities exist. Even when organisations proactively keep up to date on what's going on, they are still missing opportunities that seem to be by 'invitation only'. There was general consensus that there is value in coordination across APON members for system-change (Opportunity to find ways to do it together and make some bigger noise and create a stronger voice). It was noted however that collaboration has its challenges as well, however initiatives like APON are an important mechanism to ameliorate these challenges. The concept of quality versus quantity was raised and it was noted that there is a need to provide balanced feedback that is representative of patient populations and also, useful to decision-makers. "I think what we've been hearing that with giving feedback. It's better to have quality over quantity. Getting that balance and how to make a quality submission. Then you might hear stories about them being flooded with hundreds and hundreds of submissions and not being successful. Knowing what is the most successful approach, I think will be important for us when the time comes." The repurposing of medicines and special access was also raised. The comment was in relation to ensuring that patient organisations are able to be involved in the process so that the end result works for their patient populations. A comment was made by one organisation about the importance of keeping an active and engaged community – not only in the context of decisions about access – but to keep the community informed and empowered about all aspects of the health system. The facilitator asked if any of the organisations had been involved to date or received any communication about the National Medicines Policy review. No organisations had received any communication about this.
Observations and action items for CCDR	CCDR provided some observations and next steps from the conversations held in the webinar. **Observation 1:** It seems clear that the system and the processes at the moment that we have and the ones that even been spoken about a very HTA reactive. What we need to move towards is HTA readiness. That includes from the trial design,

	making sure the inclusion criteria is adequate for the patient population. Then by the time those trials finished to make sure that the data is being collected that can then feed into the quality of life aspect of HTA decisions. **Action item 1:** This could be something quite unique that the APON community could really look at during conferences it's maybe, rather than being HTA reactive, how can we be HTA ready. We will look into incorporating this into the APON annual conference workshop. **Observation 2:** There seems to be a challenge where patient groups have had the opportunity to provide feedback or be involved with decision-making processes or consultations. Even if therapeutics are not currently available, organisations are saying that they should still have the opportunity to engage. **Action item 2:** As a first step, CCDR will contact the Department of Health in relation to the National Medicines Policy review to alert them to the opportunity to engage with a number of organisations through APON. CCDR will further investigate mechanisms – beyond those that they currently have in place – to help patient organisations have more opportunities to engage in decisions about access.
Update from CCDR	CCDR provided a short overview of current initiatives in addition to convening this interest group, that go towards addressing some of the challenges noted in this webinar. 1. PBAC alert system and database of agenda items. When the PBAC agenda is released, we enter the items into a database on our website. This just makes it easier to see whether there are any therapies that might be of interest to patient organisations. We also send an alert to patient organisations that the agenda is available should they want to provide feeback. 2. Personal (Patient) Experience, Expectations and Knowledge (PEEK) program: This is a program for routine collection of patient experience data that can feed into various parts of the health system, including HTA. This also aims to address the challenges that have been noted about quality versus quantity and organizational capacity to collect balanced information from their patient populations. We are also working at the moment to see if we can expand this program so that the PEEK protocol is used at the end of clinical trials to collect information about experience on trials and with new treatments.