

<b>APON Interest Group</b>	Health systems and navigation		
<b>Webinar 1 date</b>	24 February 2020		
<b>In attendance</b>	Marline Monica Meredith Scott Cheryl Chris Kristina Laura Joanne Tim	Squance Ferrie Cummins Singh Talent Walker Elvidge Birks Campbell Burchell	Autoimmune Resource & Research Centre Genetic Support Network of Victoria NeuroEndocrine Cancer Australia Mito Foundation Eczema Australia Parenteral Nutrition Down Under Inc. Sanfilippo Children's Foundation MND Australia Metabolic Disorders Association Australia Mito Foundation

<b>Apologies</b>	Shirley Claire Rob Hannah David Kate Kim Christine	Baxter Leonard Anderson Heather Kernohan Wakelin Kernayres Cockburn	Cancer Voices NSW Liver Kids Australia Musculoskeletal Australia Pink Hope WA AIDS Council WA NeuroEndocrine Cancer Australia Tuberous Sclerosis Australia Rare Cancers Australia
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**Facilitator** Elle McGlynn, Senior Client Director, SenateSHJ

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

<b>Introduction and purpose</b>	<p>This interest group is to develop an understanding of how digital health and new technology is used by our patient communities, what are the barriers to uptake and how existing platforms could be leveraged for extended benefits.</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, we will use that time to design the optimal patient organisation that supports uptake of health services and allows organisations to help their patients navigate the health system.</p>
<b>Consultation question 1</b>	The facilitator explained that the first thing we are going to touch upon in this meeting relates to the current landscape and ask the question, "What has your patient population's experience been with My Health Record?"
<b>APON member feedback</b>	<p>There was one, common theme that APON members noted, being that they did not have a lot of information about uptake, but where they did have information, their sense was that uptake was poor.</p> <p>"As far as I know not many of them are using it, so there hasn't been a really good uptake with us and now we actually surveyed them GP to ask them about whether the patient were using, and I think it was only about, 10% that might of but yes there wasn't much really happening with it."</p> <p>"We don't really have much knowledge at all. The few patients that have talked to us about it, there seems to be a lot of mistrust, and a lot of misunderstanding. And,</p>

	<p>you know, they're very hesitant. I mean, I personally think it's a great idea, so I've opted into it. And I try to explain that to our members because they often go to different types of...they might go to a specialist and then a different type of specialist and then the GP.</p> <p>It's a great way to sort of keep everyone a bit more in the loop. So, you don't have to do much of the explaining, but I don't know whether it's the rollout of it, but people seem to be very suspicious. So that's my take so far.”</p> <p>“I don't think we've got a clear understanding of what people think it is about. I think we've got what the media have told us and I think we've got what the government departments have told us, and we've got some anecdotal evidence”</p>
<b>Consultation question 2</b>	The facilitator asked what patient organisations felt were some of the barriers to uptake of My Health Record.
<b>APON member feedback</b>	<p>The main themes were that there seemed to be a lack of trust and still some uncertainty in relation to what My Health Record does/how it should be used:</p> <p>“I do think there is that element of uncertainty and, and concern about the security. And I think there's also a lack of trust in how the publicity around it has rolled out as well. And I think that's compromising how people feel about it, whether they're prepared to use it or not.”</p> <p>“I think the lack of transparency or perceived lack of transparency about what the data-- how the data will benefit and what it may be used for and what it is actually legislated that it can be used for are really different things. I think that there's a lack of transparency in the media, and there's also some mischief in the media about what that narrative actually says. It's very difficult to take that back now because that horse has bolted. We're now undoing a whole lot of damage that was done because of the confusion that was caused in the rollout. I think that unless people can see the value of it, then it will continue to be a bit of a white elephant.”</p>
<b>Observations and action items for CCDR</b>	<p><b>Observation 1:</b> The main observation is that evidence is needed to understand how My Health Record has been used (uptake) and where it has been used, has it been helpful. Other questions could be asked about what additional features would make it more appealing to use and whether people intended to use it in the future, and under what conditions they are likely to use it.</p> <p><b>Action item 1:</b> CCDR will take any additional questions that APON members might like to suggest up to the end of March 2020 and then look to develop a research study based on the above.</p>