



## 2<sup>nd</sup> National Human Research Ethics Conference

### Perspectives and Change

This conference was a great example of how the virtual environment enabled a representative cross section of the ethics community from around Australia to attend a diverse, informative and at times polemic conference. It certainly provided some wonderful perspectives, some great ideas and practices, and also some confronting views. Some useful statistics to note are as follows:

- Registrations- 1528
- Attendees (registrants who attended at least one session): 1030
- Maximum attendance at a session: 467


### State of registration

State/ Territory	Number	%
ACT	59	3.9
NSW	391	25.6
NT	47	3.1
QLD	411	26.9
SA	107	7.0
TAS	29	1.9
VIC	342	22.4
WA	124	8.1
Other	14	0.9
NSW   VIC	3	0.2
NSW   QLD   SA   WA	1	0.1
Total	1528	100.0

The standard of the talks was set early by Ian Kerridge who reflected on the speed at which many publications now go online without peer-review. The subsequent plenary speakers, Ian Freckelton and Di Nicol then raised the bar with their respective talk on human challenge trials and genomic data sharing. I think the latter was my favourite talk of the conference because it put into perspective many of the issues that HRECs deal with at every meeting.

Without going into each session, the combination of dealing with vulnerabilities and consent on Day 1, Indigenous Research and HREC processes on Day 2, and University research topics and accepted abstracts on day 3 provided, I think a useful variety of talks which hopefully whet the appetite of all attendees. Of course, one cannot possibly cover all topics without having many concurrent sessions. I feel, and this was supported by the feedback, that this would detract from the ability to provide a consistent message. Although this can be ameliorated or mitigated to some extent by putting all talks online, it is clearly more beneficial for attendees to be able to absorb the talk and the messages being deposited in the chat box at the time.

There were some very memorable talks. As highlighted above, the plenary talks were information rich and very well delivered. A couple that stood out for me were Prof Norm Sheehan's off the cuff discussion about co-design of research involving First Nation's People versus Respectful design, a



difference that we are yet to fully understand I feel. Then who could forget Lewis Campbell's use of Japanese, both orally and visually, to highlight the long (narrow) road to HREC Certification in the Northern Territory. Finally, and for the second year, Andrea Calleia from Salinger Privacy delivered another memorable review of Privacy requirements which was so beneficial for all who attended. There were too many great presentations to go through, so I suggest watch the videos and absorb the views and perspectives of many great presentations.

There were clear messages that emerged. Some of these could be:

- The National Statement provides great guidance, but we should slavishly use it without reflection and consideration of contemporary views;
- Inclusion of participants in research needs to consider how inclusion can best be facilitated;
- Work is continuing on improving consent processes, but consent is not simply a set and forget exercise, but rather a continuous conversation;
- It is important to use lived experience groups as a reference for determining whether the proposed research meets the needs of that community or group. This is as applicable to First Nation's Peoples as it is to any other lived experience group;
- There is a significant difference between co-design and respectful design of research, especially in research involving First Nation's People
- The use of personal and health information should be require a clear plan of how the data will be accessed, used, stored, shared and destroyed. The use of systems such as RedCAP needs to articulate the securities and permissions that will be applied.

It is not possible to highlight the mountain of information that came out. It remains for HREC chairpersons to use the talks as resources for their own HRECs. This can help to meet annual NHMRC training requirements, but also to engender a culture of learning on an HREC, which can from time to time get stale due to the lack of time for such considered approaches.

It is important to highlight that there were some confronting messages. In one talk, attendees were treated to a view that we need to do better in relation to the use of expertise where such expertise does not already exist on the HREC. This is a useful message. It is easy to take for granted that the HREC has the expertise. However, there are many areas where this would not be the case, even for those HRECs certified by the NHMRC. The second challenging message purported a view that researchers view HRECs as a barrier or blockage to research. Personally, I do not subscribe to this, but rather that while it may be some researcher's views, these are not the majority. It does not however mean that we shouldn't always try and meet the needs and expectations of the research community. We are, after all, providing a service, and should see that we are providing the required service.

The HREC Chairpersons session, a bit like the 'celebrity squares' of the 80s, offered the opportunity to seek views from chairpersons on some curly issues such as retrospective consent, and what to do with challenging applications. I feel that this is important as a yardstick for consistency of decisions. It also helps to see the differences between University, Hospital, and on this occasion, NZ and US HRECs. Thank you to those who put themselves out there.

The feedback received has been unerringly and overwhelmingly positive. I fully take on board that we could have some talks from lay persons (as we did last year) or a consumer engagement session. This will be taken on board. Diversity is essential, as is meeting the needs and expectations of attendees. The challenge will always be how to include all the topics that we would want in 3 days. It is a great challenge to have.



On behalf of the organising committee, I am very grateful to all of the speakers who gave freely of their time and who, for the most part, were ridiculously easy to organise. Without them, this conference would not have been possible. We are pleased to be able to provide a token of our appreciation to all speakers. To the organising committee, thank you, especially to those who actively recruited some speakers.

We were delighted to continue our association with AHRECS as sponsors for the second year. This association is important as a means to coalesce all ethics-related organisations and form a much-needed community of practice. To this end, Praxis also came on board as a sponsor and provided a training session on HREC evaluation, an initiative I'm sure that is needed by all HRECs. Health Translation Queensland provided funding and administrative support in the form of the wonderful Sara Gottlieb, whom, along with this author, ran the conference. Its amazing what two people and some decent technology can achieve!

We intend to place as many of the talks as possible on the [HTQ website](#) as a resource. This will be notified to all attendees.

We are already looking forward to the 3<sup>rd</sup> conference. It is likely to largely be the same format, but you know, new committee, new ideas etc. If you are interested in being part of it, please let us know. Making it better will be a challenge, but that shouldn't stop us trying.

Kind regards

Gordon McGurk