ACPR Policy Group Meeting Minutes

Thursday 6th April 2017, Canberra
CPA 5 Ross Smith Crescent, Scullin ACT, ph: 6199 0600

Present: Sue Reid, Hayley Loftus, Angela Guzys, Elaine Meehan, Michael De Lacy, Rebecca Jarman, Sarah McIntyre, Shona Goldsmith, Isabelle Balde, Claire Galea, Nadia Badawi (via phone), Linda Watson, Eve Blair, Dylan Gration, Catherine Gibson, Kirsty Bartlett-Clark, Anna Mackey, Sue Stott

Apologies: Iona Novak, Gulam Khandaker, Alexandra Sorrhage, Rosemarie Rice, Heather Scott, Keith Edwards, Eliza Maloney, Robyn Sheppard and Christalla Louca

Opening welcome Catherine Gibson, Meeting Chairperson

Date for 2018 meeting in New Zealand (Hayley S)
It was discussed that there are many meetings on and around the next AusACPDM Meeting 2018 (potential preconference workshops on 21st, GM's 18-21st, AusACPDM 21-24 March, PZANZ 25-28th March and a CRE meeting which may be held on the 25th). In order to ensure that the ACPR meeting does not clash with any pre-conference workshops we will schedule it for the 20th March.
ACTION: *Sue and Anna have offered to book a room at the hospital for March 20, 2018.*

Country, state and territory register news (All)

WA
Linda has been working on ascertainment sources. Marie Blackmore from the Ability Centre has been of great help. Linda awaits the linkage with the Midwives Notification System and will be able to develop a new WA report once this linkage is in place. Dylan is working on congenital anomalies registers and is hoping to be able to develop the system to enable ease of linkage between CA and CP registers for future projects. The WA Register's aim is to have triplicate coding for ICD-9, ICD-10AM and Orphanet. WA is also looking at tools for remote notification for both CA and CP registers, interfacing with other systems.

QLD
Michael reported that the 2010 report has been completed and will be available via the website next week. He is pleased to report that efforts to improved ascertainment in Far North QLD have been successful. Similarly the work required between the CP Register and the new paediatric hospital in QLD (post amalgamation) has now borne fruit with good processes in place supporting ascertainment.

TAS
Kirsty reported that St Giles has employed a research assistant one day a week (Amy Cochrane) who is starting 7th April. Amy will be able to travel with Dr Maloney to attend clinics. This will be particularly helpful for capturing children who live in the North West (where ascertainment has historically been poor). Dr Maloney has now completed all her training and is providing statewide services.

NT
Rebecca has now been in the role for 6 months and is getting her processes in place. In addition to the CP Register she is beginning to plan a new paediatric injury surveillance project. It was discussed that there may well be considerable cross-over between the two projects.

VIC
Sue R reported that the VCPR is going along well. There is a new staff member Hayley Loftus who will be working on the CP Register 2 days per week. Opt-out consent now in place for both data collection for the CP register and for research invitations. A considerable amount of work is being done assisting people with recruitment for research studies.

NSW/ACT
Things are progressing well with opt-off from the three children's hospitals. Isabelle and Sarah noted 373 new cases from the first site. In the second site, 196 cases have been identified of whom 6 opted out (3 due to no longer having a clinical description of CP, and 3 that they are still being followed-up). This is a really exciting new link with CPA and the hospitals and is generating new projects. Sarah reported that they are also finding that there is considerable work required to assist with recruitment to new studies through the CP Registers.

NZ
Anna and Sue S reported that they now have opt-off consent established. In some exciting news, they have also secured 2 more years of funding for the CP register. The new governance group has been established and progress continues in establishing a national collaboration. This group is also developing new policies in relation to use of CP register data for research. There will be a CP theme to the first day of PSANZ 2018 – it is possible that this may prove an opportunity for a presentation from the NZCPR.

SA
Catherine reported that they have had a change of office location which has unfortunately taken considerable time away from their work. Catherine noted that they are considering moving to 2 year reporting for the SACPR and are pondering the possibility of opt-off consent. Catherine noted that they have new staff starting in May.

Sri Lanka Cerebral Palsy Register (SLCPR)
Ethics is through for hospital based surveillance system. Meaning that data collection can commence. Very exciting to see a new CP Register start in the region.

Bangladesh Cerebral Palsy Register
Gulam emailed a wonderful summary of the work of the BCPR which Hayley S read to the group. Some of the highlights were as follows:

The BCPR study commenced on January 2015 and is currently ongoing. A total of 726 with cerebral palsy has been assessed and registered into BCPR in the surveillance area (i.e. Shahjadpur sub district of Bangladesh). Findings: 31.8% (n=231) had Gross Motor Functional Classification System (GMFCS) level I-II, and 68.2% (n=495) had GMFCS level III-V. The adjusted prevalence of CP was 4.1 (95% CI 3.9 – 4.5) per 1000 children giving an estimated 262,400 children with CP in Bangladesh. The mean age of diagnosis of CP was 5.2 years. 9.9% (n=518) of the children wwere severely underweight and severely stunted. The aOR for severe underweight and severe stunting among quadriplegia was 5.1 and 4.9 respectively compared to monoplegia ($p<0.05$).Two thirds (66.0%) of the children had never received rehabilitation services. The mean age of first receiving rehabilitation services was 4.2 years. Parents' literacy, higher family income and severity of CP were positively associated with receiving rehabilitation services ($p < 0.005$) in the cohort. An additional 392 children with CP have been assessed from Sirajganj Sadar (nearby subdistrict). The data is yet to be analyzed.

To date 332 wheelchairs have been distributed among these children with support from Wheelchairs for Kids and Cerebral Palsy Alliance. An additional 332 wheelchairs have been shipped to Bangladesh for distribution in the upcoming months. Over 100 ramps have been constructed in the study area with support of Rotary Club of Turramurra. Four rehabilitation centres have been set up in Shahjadpur since 2015 which have the capacity to serve over 160 children annually. The development of an assistive device centre for local production of wheelchairs and other assistive devices is underway in collaboration with tna Solutions and Cerebral Palsy Alliance. 90 children have been assessed during an epilepsy camp held in November 2016 in collaboration with University of Sydney. Six more such camps will be organized by 2019 for the assessment and management of epilepsy among children with cerebral palsy.

Update/feedback on ACPR activities

Conference presentation (Sue Reid)
Sue R ran through the presentation she presented at PSANZ on behalf of the ACPR Group. It was well-received and mentioned in subsequent presentations throughout the conference. A big thanks to Sue for developing this presentation.
ACTION: *Sue R to please share slides with the group.*

Australasian Cerebral Palsy Clinical Trials Network (CRE) (Iona/Sarah/Nadia/Sue S)
This CRE has now been established. The overarching theme is to develop a network to make it easier / more efficient to conduct clinical trials e.g. an ethics officer that supports all projects. The CRE will run for the next 5 years. The CRE is keen to have a link with the CP registers. This project will be providing some resources to post-docs across the states/territories. It was discussed that there may be a joint meeting between the two new CRE's which would be fantastic.
ACTION: *Hayley S to invite Ros Boyd to the next ACPR meeting in NZ to present on the Clinical Trials Network CRE*

Genetics Summit: International Genomics Cerebral Palsy Consortium (Catherine and Sue R)
Aim to develop an international collaboration. The ACPR will be a resource drawn on in the future after the initial set-up. The next meeting will be in China, where they have 20 million births per year.

Magnesium sulphate project (Sarah)
Sarah provided a brief background summary of the work that was completed that led to the ACPR involvement as a means of long-term follow-up.
ACTIONS: *Please let Sarah know if there are new cases to your register that should be checked. Sarah will keep liaising with each state. Sue R to please send through a paper to the group re families wanting data used for research/data linkage.*

CP higher multiples study (Shona)
Shona reported on this current ACPR and SCPE research study. All states and territories have now contributed data to this study. The process to get approval for the provision of this data was slower than we had initially predicted which has posed some challenges for Asma re her time line. However Asma now has the data and is working on the analysis.

Congenital anomalies and CP (Shona)
Shona reported on this current ACPR and SCPE research study which includes both the ACPR and SCPE investigators. The study will include 10 regions, 7 from Europe and 3 from Australia. Each region has CA and CP Registers serving the same area. This work is moving forward. We were fortunate in receiving $66,000 from CPA Grants Foundation – which is being distributed between these 10 regions. Linda and Dylan in WA are striding ahead with collating the WA data. The Victorian ethics application is now in. The South Australian application is almost ready for submission. The advantage for South Australia is that they will not need to complete a linkage as both CA and CP are hosted by the same group. The Norwegian data is now ready to be sent.

ACPR paper (Claire)
Claire presented on an outline of the plan for development of the new ACPR paper. It was discussed that whilst there are alternative disability scores available it makes sense to use the same one as SCPE (as described in the paper by Elodie Sellier) to allow ease of comparison.

A discussion regarding potential weighting of data was completed. It was agreed that weighting by time (most recent birth years being more heavily weighted) is not indicated as improved medical care may result in increased cases of CP in some instance. The question of how to weight the data e.g. suppress/express data to dampen the impact of larger denominators in some states was discussed. Claire is following up with Elodie. The question of whether to use a local smoothing technique or weighted/moving averages was discussed.

Timeline: paper has to be completed by October 1st. Most probably aim for publication in DMCN.

AusACPDM 2018 - papers *(new agenda item – Hayley S/Sarah)*
Abstracts will open on May 1st and close July 2017. The question of possible new papers from the ACPR was raised:

- ACPR and SCPE comparison paper (Claire)
- BCPR papers (Gulam)
- Sue S proposed a *Stage Conversations* from the ACPR/NZCPR group. The theme is Empowerment/Partnerships.

ACTION: *Sue S to follow-up with Hayley S re the Stage Conversations concept as/if this is confirmed with Sue S and the conference organisers. Hayley S will then coordinate with ACPR Group.*

Brain-storming discussion around common issues
Strategies to engage providers who are not necessarily affiliated with your organisation (Kirsty)

- Personal contacts
- Opt-off
- Relationship building
- Administrators rather than the clinicians completing the registrations with families
- Getting the CP Register into organisational policy
- Inviting a representative from the NDIA onto the CP register advisory committee
- Contacting the other approved providers listed by NDIS
- Great benefit to having a family advisors within the governance structure
- Promote the CP register in any newsletters/websites you have available

Do individual states/territories produce their own local reports? (Kirsty)
QLD, SA, WA and VIC have produced reports which can be looked upon as models. Most groups recommended only publishing once every 5 years if your state population is small. It was also recommended that publishing papers is another way of reporting the data.

Parent occupation classification bands & how people best use these? (Anna)
Shona noted that there is a government document available from which you can search on for specific occupations.
http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/1220.01997?OpenDocument

Do people generally just write in comments section if there is evidence of PVL etc following a premature birth? Is prematurity picked up in gestational age and any additional information re MRI report etc recorded in the comments section? Terminology use of - NE and HIE - is there a preference? (Anna)

It was discussed that all of these items are entered in comments. Anna noted that a new task force is being set up in New Zealand re NE/HIE.
ACTION: *It was agreed that Anna would circulate information regarding the NE/HIE task force as it becomes available.*

Dyskinesia - CRE (Sarah)
Sarah attended the CRE meeting and an interesting presentation on Dyskinesia by James Rice. She commended the group for structuring the session so you were able to concentrate on one topic for the whole day. The question of how to describe the predominant motor type was raised. With so many children having mixed tone it can be difficult to describe which type is predominant. It is also not really representative of the true reality to describe only the predominant type – which is why an attempt was made to report more detail in the last ACPR report. The CP Description Form does assist with this issue – however you still either need to choose a predominant type or select 1 and 1 (indicating that there is no obvious predominance).
Sarah has joined the Dyskinesia Special Interest Group to keep following this process.
ACTION: *It was agreed that the CP Registers would be pleased to receive and report clinical data as recommended by clinicians in relation to predominant, secondary, mixed motor types. This could be from drawing on the CP Description Form (an electronic form is being developed in WA) or another*

system decided by clinicians. Sarah to report back any recommendations from the Dyskinesia Special Interest Group.

Usage of ACPR data (Hayley S and Sue R)
It was discussed that completing a protocol variation for CP Register ethics to allow CP Registers to be used for data linkages (particularly in relation to long-term outcome studies) should be considered.
ACTION: *Teams working on this have kindly agreed to share the details with the rest of the group so that similar protocol variations can be developed. Please send to Hayley S who will distribute (end of April 2017).*

It was recommended that we advertise on the CP Register website a clear instruction for people planning studies where they may wish to seek long-term outcome data from the CP registers through data linkage that they include the possibility of seeking long term outcome data from CP registers in their ethics applications and on the original participant consent form.
ACTION: *Hayley S/Sarah to develop some wording around this and send out to everyone for comment (May 2017)*

Research invitations (Sue R)
Victoria is doing a lot of recruitment (12 studies – 6000 first invitations sent). This is problematic as response rates are getting lower. It was discussed that this is also a problem in SA, NSW and QLD and there seems to be many PhD students and many survey based studies.
ACTION: *Catherine, Sue R and Sarah to develop an advertisement that states that mail outs of research invitations from the CP Registers only happen X times per year (in stated months) and that all ethics and Site Specific Applications etc must be submitted prior to specified cut off dates (listed). The plan will be to have the same dates across all states and territories. Isabelle to add this item to the CP QUEST agenda to get an ideas as to what families think about being contacted repeatedly to take part in research.*

New kernicterus study (Sarah)
A new CP and kernicterus study was discussed – again looking at long-term outcome of CP where cases have been lost to follow-up.
ACTION: *Commence with initial data checking (Sarah/Hayley S) after which a copy of an amended ethics approval with Low Negligible Risk application would be required for some states and others would require a full ethics application.*

A proposed data linkage ACPR and ANZNN for discussion (Sarah/Nadia)
Aim: to investigate real world rates of CP since the implementation of hypothermia and magnesium sulphate. The concept would be to complete a linkage with neither group having a copy of the linked data – but rather a separate set of data with identifiers unique to that data set. This system ensures complete anonymity and maintains the separation principle.
ACTION: All states and territories agreed in principle, as facilitating long-term follow-up using Register data is considered very important. Sarah/Nadia to provide more information as this becomes available.

Data provision - timing and reporting should we aim for earlier reporting? (Sarah/Hayley S)
The reporting of ACPR data has a significant time lag e.g. 2016 report included data 1993-2009 (6-7 years after last birth year). It was discussed that while confirmation of CP cannot be provided any earlier reporting could be streamlined by producing only a short standardised ACPR report. Additional analyses could be completed and submitted to journals as papers in the following 12 months. This has a two-fold advantage of timely reporting of data and of ensuring ACPR data is reported in the literature.
ACTION: Hayley S to develop a standard reporting template. Next data provision June 2018 (1993-2012). Aim to publish report by October-November 2018.

Dysphagia variables and relevance to respiratory health (Noula, Marie and Kate via SKYPE)
Marie Blackmore presented a summary of the work completed investigating dysphagia variables and relevance to respiratory health. At the end of this presentation it was discussed how best to

disseminate this information so that it is available to families/health professionals. It was discussed that if the Ability Centre were to develop the site for the risk calculator with corresponding advice, member groups of the ACPR would be pleased to add a link to their website to direct families to this resource:

- St Giles website
- Cerebral Palsy Alliance website
- Australian CP Register website
- IMPACT website
- ? Worth contacting the AusACPDM as the new website they are building may be a great place to house this useful information – as there is going to be a bigger focus on information for families on this site.

ACTION: *Marie and Noula to stay in touch with ACPR group as to how we can assist in promoting this excellent work. Hayley S to also put Marie and Noula in touch with Petra Karlsson. Many of these items are collected in CP Check-Up – it may fit in really well with this program.*

Social gradients and CP (Sue Woolfenden via Skype)
Sue W joined the meeting by Skype to introduce herself to the wider group which was really helpful. She has further developed the study protocol and has sent it through to everyone for comment.
ACTIONS: *Please provide feedback to Sue W on the study protocol by the 21st April.*

International CP Conference World CP Register's Day Feedback Requested (Sarah)
Planning has commenced for the next International CP Conference which will be held in Anaheim. A question as to what format we would like the World CP Register's Day has been raised by the organising committee.
The following suggestions were made by the group:

- Have a full day for this – a half day is far too short
- Recommended format: papers in the morning, discussion groups in the afternoon e.g. ethics etc and then a social event for an hour or two in the evening (nibbles and drinks would be perfect)

ACTION: *Sarah will feed this information back and Sue R has voiced her interest in joining the organising committee for this day.*