ACPR Policy Group Meeting Minutes

30th March
CAMHS Training Room Level 1, 55 King William Road, North Adelaide

Attendees:
Kate Tessman, Christalla Louca, Michael deLacy, Catherine Gibson, Rosie Rice, Heather Scott, Linda Watson *(Meeting Chairperson)*, Eve Blair, Madeline Rowell, Elaine Meehan, Sue Reid, Sarah McIntyre, Shona Goldsmith, Isabelle Balde, Iona Novak, Nadia Badawi, Hayley Smithers-Sheedy, Sue Stott, Alexandra Sorhage **Guests:** Michael Msall, Wendy Scheil and Emily Sheppard **Apologies:** Alanna Barr, Gulam Khandaker, Eliza Maloney, Anna Mackey, Iona Novak (morning session), Dinah Reddihough

State/territory update

WA (LW)
The CP Register is now held in the Dept of Health. There have been some difficulties in funding data linkages which is particularly important for the congenital anomalies register. Linda was pleased to report that there is a current linkage with the midwives dataset which is underway. After this linkage is complete Linda will be producing a new WA report.

A meeting with the head of the diagnostic imaging unit was productive. Linda now has an automated system for working with this team. During the meeting the SCPE MR Classification scheme was discussed and they will be looking at this together in the future. Gareth Baynam who is the head of WARDA has an on-line system that will code from text. Linda is going to trial this system for neuroimaging data.

Linda is also working with the Ability Centre to try and streamline the consent process. She has been discussing using the CP Description form with this group. (This tools is used in VIC for research and in NSW as part of CP Check-Up).

VIC (SR, EM)
The CP Register is temporarily suspended. The team are responding to a change in the requirements in relation to consent processes. Sue and Elaine are re-writing protocols and responding to this request. The VCPR has now contributed to more than 100 papers and 100 research projects and is a wonderful example of the power and cost-effectiveness of what can be achieved through the work of CP registers.

Meeting participants suggested that it was discussed that ensuring adults with CP/disabilities have a voice on ethics committees can be helpful in this instances. Linda noted the WA experience, where advocacy of people with CP and their families in WA has led to support for the WA CP Register and mandatory reporting.

In happy news it was noted that Elaine has nearly completed her PhD using CP Register data. Her thesis reports patterns and costs of admissions to the emergency department for children with CP.

NSW/ACT (SMc, IB, IN, SG)
On the 23rd December ethics approval was granted for the three children hospitals in NSW to allow opt-off registration for the CP Register. The medical rehabilitation teams at these hospitals have assisted in this process. The plan is to do now complete an opt-off once a year. Sarah has a clinical position at the hospital to support this process around recruitment.
Over the last 12 months we have had increasing numbers of research projects requesting recruitment from the CP Register.
A goal for 2016/17 is to identify a suitable interested ACT representative for the CP Register (perhaps an obstetrician).

TAS (MR and RS)
Madeline Rowell has been recruited to St Giles for the Tas CP Register which is fantastic. Robyn and Madeline are currently working on ascertainment and pushing recruitment with the aim to refine the recruitment process with Dr Eliza Maloney.

SA (CG, RR, HS)
The team in SA are pleased that the 2014 report was printed before Christmas 2015. The next 2015 report has just been closed off and the team are working through the approval process with the aim for this next report to be available at the end of 2016.

Five year assessments continue, but have been streamlined to occur with other medical appointments.

In other work, the team are working on contacting adults with CP who are registered as children with the CP Register to provide the option to reconfirm their consent as adults. This is an annual process.

NT (KT)
Kate reported that the NT now has 157 registered cases and have reached minimum level of ascertainment. She reported that the Darwin registrations are captured well at clinics, with visiting clinicians from Adelaide at specialist clinics. She reported she would like to improve the ascertainment in Alice Springs and remote regions. The new plan is to for CP registrations to be collected at the rehab clinics in 2016/2017.

QLD (MdL, CL)
Michael was pleased to report that funding for the CP Register has been confirmed until 2019. The team will continue to work hard to show the usefulness of the CP Register. In a recent meeting with the NDIA they were able to show the supplement and have been asked by the NDIA to pursue other questions.

The new ethics is complete and systems are running well, starting with Opt-on. No one has declined an invitation to participate in the CP Register this year. Michael has also been visiting groups in Far North Queensland, which has been opportunity to develop partnerships and has yielded 30-40 new registrations to date.

The steering committee for the QCPR will be changing slightly in 2016 as some of the positions have changed.

NZ (SS, AS)
Sue reported that the NZ CP Register has now been active for one year, and they have 140 cases. The web-platform has now been modified to meet NZ needs. Interestingly, 15% of registrations have been self-registered by families and individuals with CP. The NHI number is included on the CP register – took more than 12 months to get this sorted but has been an important step. Next step for the group will be to investigate the process for opt-off consent. Sue and Alexandra felt that Indigenous groups are not currently been captured on the CP Register and opt-off would certainly assist with ensuring representation of these groups in the CP Register.

Bangladesh (HSS)
Hayley reported on behalf of Gulam Khandaker who with Prof Muhit and colleagues from the Child Sight Foundation, heads up the Bangladesh CP Register. Gulam and the team have now more than 600 registered cases on the BCPR and have established partnerships with Wheelchair for Kids to provide equipment to children in Shahjadpur (the sub-district where the CP Register is located). The team have also recently launched the Bangladesh CP QOL study. Gulam is working with Nadia and Hayley to establish additional CP registers in the region.

Chicago (MM)
Michael Msall described the Chicago CP Register as more akin to a patient outcome dataset. There are now more than 2000 individuals registered. Michael is working on young adult modules at the moment with Paul Grosse and colleagues. This is part of the AACPDM common data elements project. The group has been working with the GM's with the aim to provide greater opportunity for early detection of CP. Michael has recently been investigating the administrative prevalence of CP and will be presenting this information at the conference in Sweden.

ACPR research outputs

ACPR Supplement
Thanks to Nadia Badawi for initiating the development of the supplement and to Sue Reid, Catherine Gibson and Eve Blair for their editing of papers and to all contributing authors for their hard work. The ACPR Supplement has now been printed and copies will be disseminated to those groups who responded to our previous International CP Registers survey and to other stakeholders such as the Department of Health. If you require additional copies of the supplement please contact Hayley and she can arrange for these to be sent out to you.

The policy group wished to formally minute their thanks to Rob White for his support of the Australian CP Register and his support to have the supplement published.

Research Briefing (HSS)
The next CP Foundation Research Briefing in Sydney will occur in May. Sue Reid has been asked to present her paper on declining severity and prevalence of CP in Victoria. Hayley will report her findings from the congenital cytomegalovirus study.

cCMV and the APSU (HSS)
The Australian Paediatric Surveillance Unit has a national congenital cytomegalovirus surveillance program. Following recent meetings, the investigators from the study are interested to gather more data regarding cerebral palsy and motor impairment

variables within this project. Hayley and her PhD Supervisor Cheryl Jones are working with the APSU on securing these new additional fields.

Future papers (HSS)
There are currently numerous CP Register projects which will result in new knowledge and also future papers for the ACPR.

These include:

- ACPR/SCPE: higher multiples,
- ACPR/SCPE: congenital anomalies
- Hypotonia paper
- MgS04 outcomes
- Summary paper from the next ACPR report

When planning new research please consider opportunities to work with your state/territory counterparts to increase your study numbers, work with your talented colleagues from other states, share your skills and generate new research outputs for the ACPR.

ACPR Report – progress to date and to do list (HSS and CG)

Hayley provided an updated report timeline for the group with the aim for completion of the ACPR report by July 2016.
Two state CP Registers (Queensland and the Northern Territory) have now reached the minimum ascertainment level of 1.5 pre/perinatally acquired CP cases per 1000 live births, which is a fantastic achievement. The question of whether to include this state data in the calculation of rates was discussed. It was agreed that the inclusion of this data would skew rates resulting in an under-reporting of the true rate of CP in Australia and make comparison with previous reports problematic. Michael (QLD) and Kate (NT) agreed that data from the long established CP registers (SA,VIC and WA) should be used for the calculation of rates and to allow long-term comparison over time.

Hayley presented ACPR data regarding gestational age, type and topography of CP and GMFCS for the group to discuss. It became apparent that the large numbers of cases now included in the report data >7000 has meant that the proportions of variables of interest are the same whether only population state data is included or all state data. It was agreed for this report that all state/territory data would be included in the tables and figures as long as there was no more than 20% missing data available for the variable in question. This variation in reporting will be noted in the methods section of the ACPR report.

Catherine discussed the importance of including all cases born in a state/territory in the ACPR dataset and count. In those instances where a state may not be aware of case born in their region but living elsewhere this can be difficult. It was agreed that a regular time for checking that all registered cases born in each state are known to that birth state (in deidentified format as/if required) is key. It was agreed that Hayley would facilitate this process on an annual basis.

Genetic causes of CP (SS)

Sue Stott presented a case describing an individual with a rare genetic condition which has a phenotype that meets the requirements for CP. It was discussed that as genetic testing becoming more accessible in terms of availability and costan increasing number of families are identifying rare genetic mutations as the underlying cause/contributing cause of their child's movement disorder. It was discussed that the principles discussed in the What constitutes CP in 21st century paper (the appendices are also included on the ACPR website) are quite helpful here in terms of whether a cerebral palsy description continues to be relevant for these individuals i.e. if the definition of CP is met (see SCPE five elements) then the child can continue to be included under the CP umbrella.

Magnesium Sulphate (SMc and Emily Shepherd from the University of Adelaide)

Emily presented an overview of the research history and implementation of MgS04 in Australia. Following the WISH project (implementation of the clinical guidelines), this intervention is now well-implemented across Australia with approximately 85% of eligible mothers in preterm labor (<30 weeks) receiving MgS04. Sarah will be in contact with those who are involved in the long term follow up of WISH (SA, Qld, NSW and NZ).

In the new ACTOMgSO4 data linkage project, information in the initial ACTOMgSO4 trial will be linked with the information that has been collected by the Australian Cerebral Palsy Registries in order to optimise the identification of children in ACTOMgSO4 with a diagnosis of cerebral palsy. This study will obtain the most accurate estimates possible of cerebral palsy rates for the groups of children born to mothers who received magnesium sulphate or placebo in ACTOMgSO4. This is essential for assessing the long-term effects of this therapy. This is an exciting new role for the CP registers and will make a real contribution to the research in this field. Ethics processes are currently underway to allow this work to proceed.

SCPE Projects (SG)

Congenital anomalies

A survey of cerebral palsy and congenital anomalies registers was completed. This was used to determine potential interest in the study and to identify areas of possible geographical overlap of CP Register and CA Registers in Europe (Eurocat) and Australia. The group recently submitted a large research grant but was unsuccessful, so the plan is to proceed and complete the project within current resources. A protocol and NEAF have been commenced for this project. SA and WA have agreed in principle that they would be involved in this study and Shona will be following-up with WA and SA as to ethics processes and approvals required. It was discussed that the Victorian CP register would like to be involved but the Victoria CA Register has some difficulties with ascertainment currently. Sue will liaise with Sarah and Shona about this.

Multiple births projects

Shona, Sarah and Hayley are working with Elodie Sellier and Asma Fares re CP and higher multiples. It has been resolved that for calculation of rates of CP amongst higher order multiples only the SA,VIC and WA CP data and denominators should be added to the SCPE data. For description of CP amongst higher multiples (e.g. type and GMFCS) all state and territory data can be included. Moving forward, ethics approval for all states and territories to include their deidentified ACPR data will be sought. SG and HSS will follow-up with QLD re numbers of Quads. Specific ethics requirements for SA, WA and Vic are currently being followed up.

Recent Survey re Hypotonia, Minimally severe CP, ABI and postneonatally acquired CP (SMc)

The survey results and the outline of the workshop were presented to the meeting. There appears to be little agreement on inclusion criteria around these descriptors. The completed survey and results of the workshop will contribute to the next round of the Delphi study.

Perinatal variables (LW)

Linda is currently completing a linkage with the midwives data collection. Many although not all data points of potential aetiological relevance previously discussed are included in this linkage. It was agreed that each CP Register should investigate whether these and other items listed are available for linkage in their state/territory.

Communication classification systems for CP Registers (MD)

This discussion followed from previous meetings that considered the addition of CFCS and Viking Scales to the MDS. It was agreed that the Viking should be collected as it is an important descriptor of speech production and is being collected by CP Registers internationally. The Viking is also reasonably easy to collect. The CFCS and FCCS both classify the effectiveness of communication. The CFCS is already collected across some states and is used internationally, the FCCS has been recently published and is used in Queensland. It was discussed that the FCCS and CFCS collect very similar information and could be harmonised in terms of data reporting.

It was agreed that Hayley should amend the MDS and ACPR database to include these (drafted below Actions table below).

The EDACS was also discussed briefly at this time. It was agreed inclusion of the EDACS should be discussed at the next ACPR meeting after the conference in Stockholm where data on the EDACS is being presented.

CP Quest (SMc)

A new parent group called CP Quest has been established at Cerebral Palsy Alliance. Among its functions it aims to provide advice to Cerebral Palsy Alliance's Research Foundation and Research Institute from the perspectives of people with cerebral palsy and their families. We hope that this group will be able to provide advice to the NSW/ACT CP Register and members of the CP Alliance Research Institute team.

Many of the state and territory CP registers have people with CP or parents of people with CP on their steering committees. The ACPR does not have this involvement at the current time. When Hayley and Sarah attended the SCPE meetings in Europe, the meetings were open to families who self-selected whether they wanted to attend and which groups they participated in.

It was agreed that Sarah and Hayley would develop some models to consider to involve families/people with CP in the workings of the ACPR. In discussions on this point it was noted that the meetings are getting quite large and that perhaps a new structure to the meetings may be helpful e.g. policy meeting in the morning and working groups in the afternoon (with increased number of participants).

New platform for the ACPR (HSS)

A new web-platform for the ACPR has been developed by Paul Novak. This will allow the register to be more accessible on ipads, iphones etc. Hayley is currently trialling the system which may require some small tweaks prior to the transition. We will ensure plenty of warning for this transition and ensure all data is transferred.

Other business

Australasian Cerebral Palsy Strategy (NB)

Nadia reported that a new Australasian CP Strategy is currently under-development. This project is a collaboration between Cerebral Palsy Alliance, Ability First Australia, Cerebral Palsy Australia and AusACPDM and consumer representatives. This work is being coordinated by Ingrid Honan at the Cerebral Palsy Alliance.

Meeting Chairperson

The ACPR has had the pleasure of having Linda Watson as the meeting chairperson for the last few years. As this is a rolling position it was discussed that it was now time for a new chairperson. Catherine Gibson has kindly agreed to take on this role for the next 2 years – thank you Catherine.

Next meeting

No new meeting date and time were set. The next meeting will be called as required in relation to the work on the ACPR report. Otherwise the next meeting will take place after the International CP Conference in Stockholm (June).

Actions

ACTION ITEMS	PERSON RESPONSIBLE	DATE
Request to share digitalised version of CP Description Form	Sue to send to Michael	End April 2016
Request for Catherine and Sue to share their register re-consent letter for adults with CP with the group (send to Hayley for dissemination)	Catherine and Sue	End April 2016
Update methods section of the ACPR report	Hayley and circulate to all	End May 2016
Annual check re cases with a different birth state to case state	Hayley to facilitate all groups to check this	Annually in August
Congenital anomalies project ethics requirements	Shona to follow-up with SA and WA	As required
Congenital anomalies project, potential for inclusion of Victoria	Shona to discuss with Sue	As required
Multiple births projects – ethics follow-up	Shona, Hayley and Sarah to continue to follow-up.	As soon as possible
Hayley will send through two lists i) ACPR wish list and ii) Linda's midwives document. Please identify which variables are available to your group through local data linkage.	Hayley and All	End July
The data fields for Viking and CFCS/FCCS have been provided below. Please feedback any thoughts to Hayley.	All	End May
EDACS to be included as an agenda item for the next meeting after Stockholm.	Hayley	Next meeting
Development of new models for meeting structures and greater inclusion of families/people with CP to the ACPR	Sarah and Hayley to circulate	End July

Draft of New Fields

Field Name: viking
Description: Viking level at age 4 years+

Field Size: 1
Field Type: Numeric

Values: 1 = Level I
2 = Level II
3 = Level III
4 = Level IV
9 = Unknown

Field Name: CFCS
Description: Communication Function Classification System at 4 years+

Field Size: 1
Field Type: Numeric

Values: 1 = Level I
2 = Level II
3 = Level III
4 = Level IV
5 = Level V
9 = Unknown

Notes: Please included the CFCS **or** FCCS in addition to the Viking data where this data is available.

Field Name: FCCS
Description: Communication Function Classification System at 4 years+

Field Size: 1
Field Type: Numeric

Values: 1 = Level I
2 = Level II
3 = Level III
4 = Level IV
5 = Level V
9 = Unknown

Notes: Please included the CFCS **or** FCCS in addition to the Viking data where this data is available.