MACH
Melbourne Academic
Centre for Health

MacHSR Future Leaders Fellowship program
Final reporting (Cohort 2)

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Project title: Exploring the service gaps in access to allied health early intervention services for infants with prenatal exposure to alcohol and/or other drugs (AOD) attending the WADS follow up clinic at the Women's Hospital, Melbourne

Report:

The problem
Infants who are exposed to alcohol and/or other drugs (AOD) *in utero* are highly vulnerable and at risk of adverse developmental outcomes (Symons, Finlay-Jones et al. 2022). The use of illicit substances during pregnancy is a growing problem worldwide (Wouldes and Lester 2019, Yeoh, Eastwood et al. 2019, Lowe, DiDomenico et al. 2022). In Australia, a 2013 survey by The Australian National Drug Strategy Household Survey reported that up to 4% of all pregnant women used illicit substances during their pregnancies. Furthermore, in an Australian cohort of 2146 pregnant women, 11.3% reported drinking high levels of alcohol (more than 7 drinks per week) at some stage during their pregnancy (Muggli, O'Leary et al. 2014).

There is increasing evidence of the need for neuro-developmental surveillance and early intervention for infants exposed to AOD *in utero* (Yeoh, Eastwood et al. 2019, Arter, Tyler et al. 2021), however at present the population is under-researched and there is a lack of robust evidence on the long term developmental outcomes of these infants due to a scarcity of prospective, longitudinal studies (Fucile, Gallant et al. 2021). Furthermore, most of the existing literature related to developmental outcomes for this population is from the USA and there is limited published research for the Australian population (Harst, Deckert et al. 2021). A number of authors have suggested there may be differences in the prevalence and trends of substance use between Australia and the USA (Maxwell 2003). There are a number of country specific factors that may impact on the prevalence and trends of substance use (McBride, Teesson et al. 2009). These may include social and cultural factors as well as substance availability. It is therefore important to explore what is happening within the Australian cohort of infants exposed to AOD *in utero*.

The Women's Alcohol and Drug Service (WADS), based at the Women's Hospital, Melbourne cares for approximately 100 infants exposed to AOD *in utero* each year. These infants are reviewed in an outpatient clinic by a paediatrician who monitors their growth and development over the first 2 years of life. At present there is no clear pathway for allied health involvement in the assessment and management of these infants, no clear time points for developmental monitoring and no standardised developmental screening tools being administered to determine which infants need further assessment or support. As such, referrals to allied health are limited and occur on an ad hoc basis, resulting in significant variations in the care received. Furthermore, the literature suggests a lack of standardised developmental monitoring and support for this population and a need to create/improve clinical practice guidelines with standardised outcomes that are assessable and meaningful (Welton, Blakelock et al. 2019, Shan, MacVicar et al. 2020).

Refinements to the project and barriers encountered
The original plan was to improve access to allied health services for these infants by developing and implementing an equitable pathway to allied health access. It soon became apparent this was far too ambitious an aim for a 12-month project especially given the lack of existing clinical practice guidelines for the population. Therefore, the aim shifted to exploring the clinical utility of using the Brigance III Infant Screen – a standardised tool that measures multiple developmental domains. Unfortunately the Australian supplier of the Brigance closed down and the tool was not available for purchase in Australia so the project had to pivot once

again. The final project evolved into a Retrospective Cohort Study looking at the gaps in access to early intervention allied health services for infants exposed to AOD *in utero* at the Women's Hospital, Melbourne.

As this was a retrospective study, we were only able to collect demographic data that were available in the electronic medical record (EPIC). Therefore, information that was not routinely collected, but may have been relevant to the vulnerability of our cohort, was not available.

This study involved reviewing the files of infants born during 2021. This timeframe was chosen as it was the most recent cohort that had completed their 2-year WADS follow-up period at the time of the study commencement. However, it is impossible to ignore the potential impact of COVID-19 and associated restrictions on factors such as the number of face-to-face clinic appointments attended.

Some of the additional barriers encountered were the researcher's own limited experience with interpreting results and lack of access to a statistician. Fortunately given the small subject numbers and the focus on descriptive statistics this was not a significant problem.

Activities/achievements

Methods
A retrospective observational cohort study of infants who were exposed to alcohol and/or other drugs *in utero* and who were linked with the WADS service at the Women's Hospital, Melbourne was completed. Infants born between 1/1/2021 and 31/12/2021 were included.

Data were collected from EPIC of infants who attended one or more outpatient clinic visits in the WADS clinic. Demographic information including sex, date of birth, gestational age at birth, 1 minute Apgar score, birthweight and head circumference were extracted from the electronic medical record. Birthweight and head circumference z scores were calculated using WHO (WHO Child Growth Standards) or Fenton (Fenton and Kim 2013) growth charts as appropriate for gestational age at birth. The number of reported antenatal substance exposures, neonatal length of stay in complete days, admission to NICU/SCN, inpatient allied health review physiotherapy, occupational therapy and speech pathology), the involvement of child protective services and whether infants were discharged after birth to maternal care were also extracted from the electronic record.

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Data were collected on infants' attendance at WADS follow up clinic appointments including the number of appointments attended, the corrected age of the infant at each attendance, any documented developmental assessments or concerns and whether there was any involvement of or referrals to allied health and at what infant age these occurred. Additionally, it was noted whether the infant had had more than one primary caregiver during the follow up period.

Information about an infant's age at their last WADS clinic attendance was also extracted. The level of ongoing care for each infant was recorded, where available, and it was noted whether the infant was actively discharged from the WADS service or whether they were lost to follow up.

Results - descriptive summary
Sixty-three infants exposed to AOD *in utero* were included. Infants attended a median 2(range 1-5) appointments and only 28(44%) continued follow-up beyond one year. Neurodevelopmental concerns were clearly identified in 17(27%), and unclearly in 9(14%). Of 26(41%) infants with potential concerns, 12(46%) were referred to allied health early intervention services. No standardised neurodevelopmental assessment tool was used. (see appendix 1 for results table)

Achievements
An abstract has been submitted to the Australian Association for Infant Mental Health for a poster presentation at the upcoming November conference in Sydney.

Plans for continued activity/translation/implementation

The current study explored current allied health involvement with this cohort as well as gaps in neurodevelopmental surveillance and support for the population and potential areas for service improvement.

The diagnostic guidelines for infants at risk of Fetal Alcohol Spectrum Disorder (FASD) (that is, infants who were exposed to alcohol *in utero*) suggest that clinical observations are not sufficient for assessing development and that standardised assessment tools should be used (Bower, Elliott et al. 2017). It is also recommended that assessment of infants at risk of FASD is performed by a multidisciplinary team which includes allied health professionals (Bower, Elliott et al. 2017). Results from this study showed that none of the infants had any standardised developmental screening or assessment tools used to monitor their development which represents a significant gap in the neurodevelopmental monitoring of infants within our cohort. Additional research needs to explore appropriate objective measures to assess development and develop equitable referral pathways to allied health. Now that the Brigance III is once again available in Australia we hope to explore the clinical utility of this tool in our follow up clinics as originally planned.

The importance of early intervention for infants at high risk of adverse neurodevelopment has been well documented (Orton, Olsen et al. 2018, Spittle, Anderson et al. 2021). At the time of this study there was no funding for paediatric allied health within the WADS service at the Women's. This was likely a contributing factor to the limited number of allied health referrals, however the fact that there were a number of infants where neurodevelopmental concerns were identified and no allied health referrals were made represents a significant service gap which cannot be ignored.

Whilst this project was undertaken the WADS team at the Women's hospital were successful in obtaining philanthropic funding for a First Thousand Days Clinic which includes physiotherapy input. The commencement of this service, contemporaneous with this research project, demonstrates recognition of the need for more allied health involvement in the neurodevelopmental surveillance and support of this highly vulnerable cohort. Further work needs to be done to ensure the role of other paediatric allied health professionals is acknowledged and they are also funded to provide support to these infants.

The literature suggests that for infants exposed to alcohol and/or other drugs *in utero*, many may appear to have development in the normal range early on but neuro-behavioural concerns including cognitive and language issues become evident in the 2nd year of life (Benninger, Borghese et al. 2020) (Lowe, DiDomenico et al. 2022). For the 56% of infants in our cohort who were discharged or lost to follow up prior to 12 months corrected age this represents a missed opportunity to identify neurodevelopmental concerns and implement appropriate allied health early intervention supports. Therefore another area for future focus must be how to optimise longitudinal engagement of these infants in neurodevelopmental surveillance and support services.

Future research should aim to develop an evidence-based approach to reducing the variation in developmental monitoring and support for infants exposed to drugs and alcohol *in utero* and improving equity of access to allied health for these infants. It is anticipated that this will, in turn, provide opportunities to improve the developmental outcomes for these infants.

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APPENDIX 1 - RESULTS

Table 1 - Participant characteristics

	Total birth cohort n=89	Follow up cohort n=63
Female n (%)	41 (46)	27 (43)
GA completed weeks median (range)	38 (23-40)	38 (34-40)
Birth weight in grams mean (range)	2812 (553-4220)	2951 (1198-4220)
Birth weight z-score median (range)	-0.42 (-4.08-1.65)	-0.70 (-4.08-1.65)
Head circumference* in cms median (range)	33 (21-36) (n=88*)	33 (27-36)
Head circumference Z score* median (range)	-0.51 (-5.2-1.22)	-0.82 (-5.21-1.22)
Apgar score at 1 minute median (range)	9 (2-9) (n=88)	9 (2-9) (n=62)
Born at RWH n (%)	87 (98)	62 (98)
Inpatient length of stay median (range)	7 (1-40)	7 (1-122)
Neonatal discharge to maternal care n (%)	N/A	39 (62)
Known to have more than 1 primary caregiver during WADS follow up period number (%)	N/A	20 (32%)

Table 2 - Recorded *in utero* exposures

	Total cohort n=89	Follow up cohort n=63
Alcohol n (%)	19 (21)	14 (22)
Methamphetamines n (%)	56 (63)	40 (63)
Cannabis n (%)	59 (66)	42 (67)
Benzodiazepines n (%)	17 (19)	13 (21)
Opiate n (%)	12 (13)	10 (16)
Opioid substitute treatment n (%)	16 (18)	12 (19)
GHB n (%)	10 (11)	9 (14)
Other illicit n (%)	7 (8)	5 (8)
Number of reported exposures (median and range)	2 (1-5)	2 (1-5)

Table 3 - clinic/allied health service gaps for the follow up cohort n = 63

	n = 63
Total number of WADs clinic appointments attended for the cohort	127
Number of WADS clinic appointments attended per infant median (range)	2 (1-5)
Standardised developmental screening tool used at any stage	0
Corrected age (CA) at last WADS clinic attendance in months median (range)	10 (2)
Number of infants who attended last WADS clinic appointment at < 12 months CA	35
Discharge destination at <12 months CA Appropriate* Inappropriate	 6 (17%) 29 (83%)
Number discharged 12-24 months CA	28
Discharge destination at 13-24 months CA Appropriate* Inappropriate	 21 7
Referred to allied health support (n = 12) By WADS clinic team By external service	 10 2
Neurodevelopmental concern identified at any stage	17 (27%)
Number of infants referred to allied health	12 (19%)

* For the purposes of this study, appropriate discharge was considered as discharge to the ongoing care of a specialist or general paediatrician (or discharge to ongoing care by GP at or above 18 months corrected age). Inappropriate discharge was classified as lost to follow up prior to 2 years corrected age or discharged to GP follow up prior to 18 months corrected age

APPENDIX 2 - REFERENCES

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