The changing face of FASD & the role of the paediatrician:

National case surveillance findings 2014-2017

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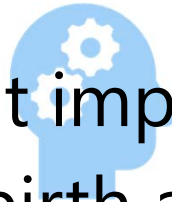
Reporting paediatricians

What is Fetal Alcohol Spectrum Disorder (FASD) *Why is it important?*

Tip of the iceberg: neurodevelopmental & physical effects of prenatal alcohol exposure



Acquired brain injury: severe neurodevelopment impairment

+/- Physical features: facial, growth deficits, birth anomalies (biomarkers)

Preventable, common cause of neurodevelopmental disability

FASD epidemiology in Australia

Previous national surveillance

FAS/PFAS (2001-04) *Elliott et al*

92 cases, incidence rates considered underestimate

Prevalence studies

Lililwan: high risk community in WA - *Fitzpatrick et al - FASD 20%*

Youth in detention in WA (Banksia Hill Project) - *Bower et al - FASD 36%*

Important studies, yet not representative of national population

What this study adds

Australian context

The **first national** study to identify children across the **entire FASD spectrum** using updated criteria (2016)*

Includes FASD without physical features

Precursor to national registry (FASDAR)

International context

The only national FASD surveillance study

Comparison to Canadian FASD registry possible

* Bower C, Elliott EJ 2016, on behalf of the Steering Group. Report to the Australian Government Department of Health: "Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)"

What data have we captured?

Diagnostic patterns

- Clinical patterns
- Who / where are children diagnosed?

Demographics

Changes over time

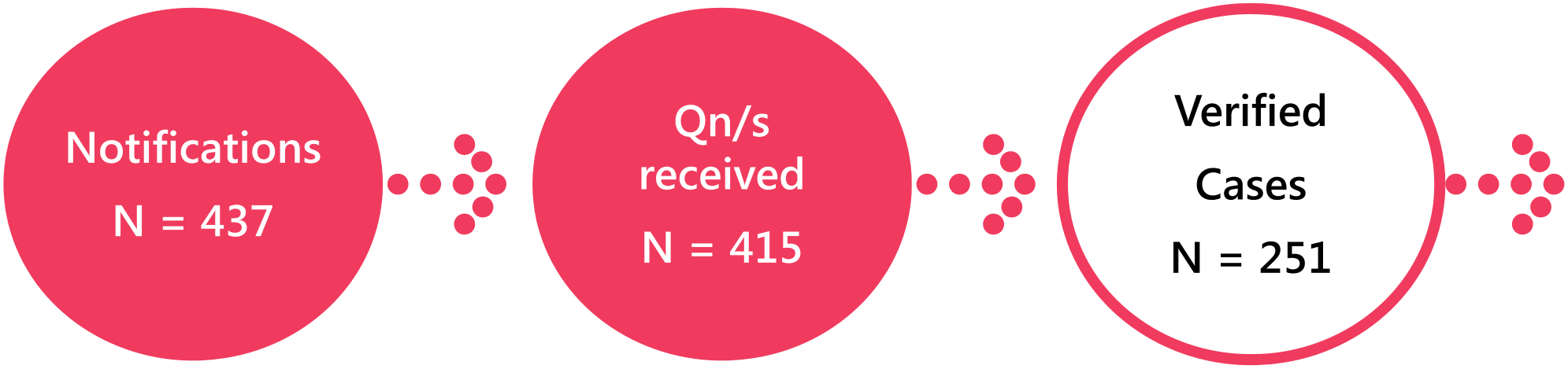
Methods: Case finding

What?	• **Active surveillance** • **Prospective national case-finding**

Who?	• **Children/adolescents < 15 years old**
	• **Reporters: ~1500 paediatricians**
	  • **%90 paed. in Australia**
	  • **Monthly response rate 80-90%**

When?	• **December 2014 – Dec 2017**
How?	• **Paediatrician reporting case completes questionnaire**

Verified cases: Dec 2014-Dec 2017



Age>15y/diagnosis date n= 96
Criteria not met n=10
Not yet classified n=21

Methods: Diagnostic criteria

FASD + 3SFF	**Prenatal alcohol exposure** (+/-)	**Severe Neurodevel. impairment**	**3 Sentinel Facial features**
FASD < 3SFF	**Prenatal alcohol exposure**	**Severe Neurodevel. impairment**	**0,1,2 Sentinel Facial features**

FASD Classification (n=251)

FASD +3SFF	**24 %**	Median age	7.6y*
		Female:male	1 : 1.6**
FASD <3SFF	**76 %**	Median age	9.2y
		Female:male	1 : 1.9

* Significant difference (*p<0.001*)
*** No significant difference (p = 0.59)*

Prenatal alcohol exposure

19% used standardised tool (typically AUDIT-C)

High risk exposure

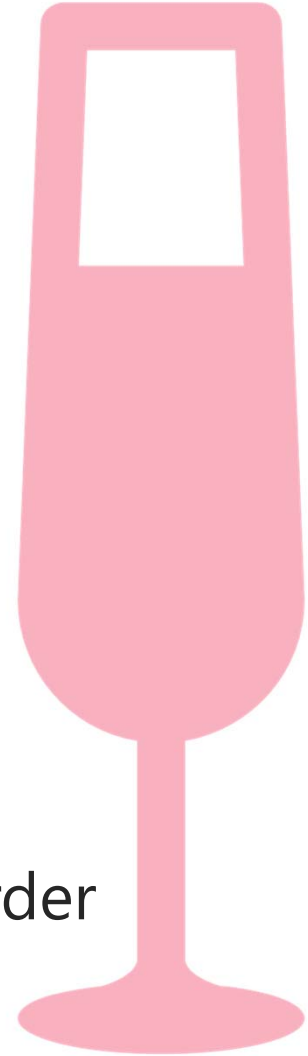
40% **7+** std drinks *per week*

32% **5+** std drinks *on a single occasion*

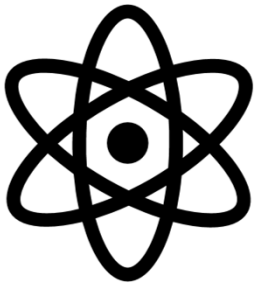
Risk level not reported in ~60% of cases

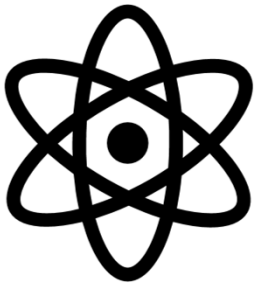
41% birth mothers reported to have alcohol use disorder

18% alcohol related health problems/injury



Neurodevelopmental Domains

				
Brain structure /neurology	**Motor skills**	**Cognition**	**Language**	**Academic Achievement**
Memory	**Attention**	**Executive function, Impulse control Hyperactivity**	**Affect Regulation**	**Adaptive behaviour, Social skills, Social comm.**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		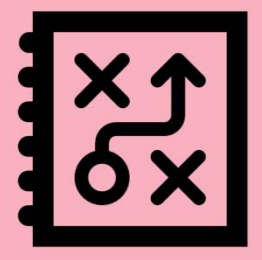		
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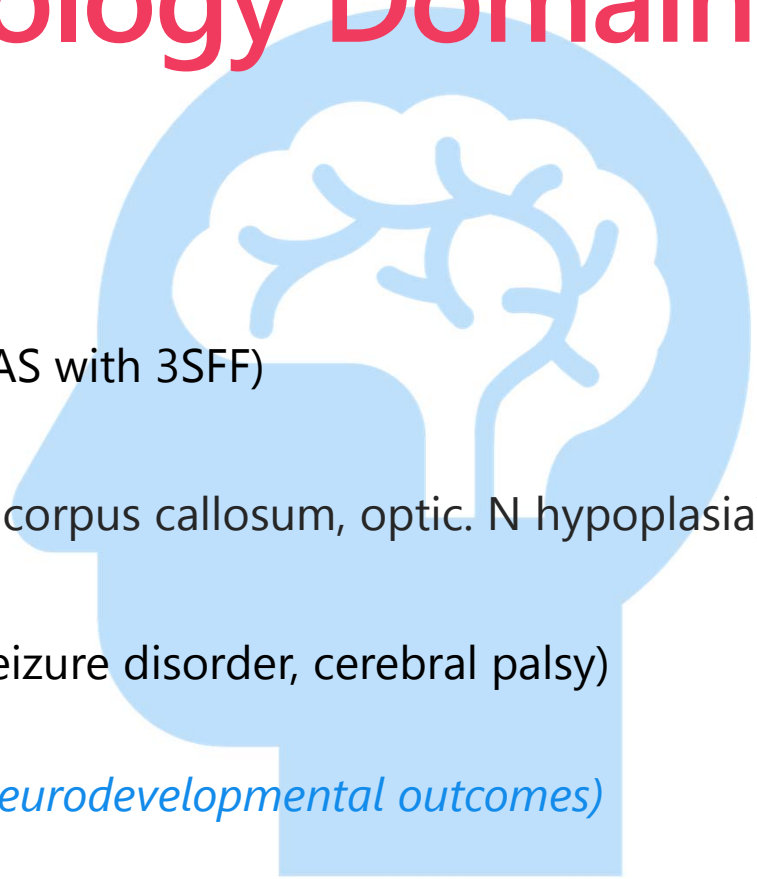
Neurodevelopmental Domains

Brain structure/Neurology Domain



24% **Microcephaly** (~correlates with rate of FAS with 3SFF)

14% **Structural brain anomaly** (e.g. thin corpus callosum, optic. N hypoplasia)

8% **Neurological abnormalities** (e.g seizure disorder, cerebral palsy)

25% ***Growth impairment*** *(correlates with neurodevelopmental outcomes)*

Facial features

40% Short palpebral fissures

57% Smooth philtrum

47% Thin upper lip

Photo analysis software used in 60%

Demographics

Diagnostic patterns

Demographics

	FASD 2014-17	FAS 2001-04
Age at diagnosis (median)	**8.6 y** ←	3y
Male:female ratio	1.3:1	1:1
Child protection services *(current/past)*	75%	67%
Out of home care *(foster/adoptive)*	**54%** ←	38%
Biological parents' care	18%	40%
Grandparents' care	16%	21%
Sibling with FASD	15%	51%
Indigenous	**57%** ←	65%

WA 70%, 43% elsewhere

3% general population

Change since previous study 2001-2004

Reporting rates quadrupled

- 2014-2017: *84 per year*
- 2001-2004: *23 per year*

Incidence tripled

- 2014-2017: *1.79 per 100,000 children < 15y*
- 2001-2004: *0.58 per 100,000 (FAS/PFAS only)*

Similar ratio 3 SFF : <3 SFF

- 1:3
- as expected given what we know about FASD

Who is diagnosing FASD and how?

84% diagnosed in specialist FASD clinics / by FASD champions/experts (in MDT teams)

- **7 paediatricians**
  - 18% (of 38 reporting paed/s *for FASD*)
  - 0.005% (of 1500 reporting paed/s *to APSU overall*)

Specialist FASD clinicians more commonly diagnosing FASD with <3 SFF:

- **82% vs 61%** *p = .006*

Where is FASD being diagnosied?

State/territory distribution

Gen population

FASD population

Reporting patterns: *Discussion*

Possible reasons for regional variation

Differences in drinking patterns in different regions

?Real differences in prevalence

Under vs over diagnoses

Access to diagnostic services

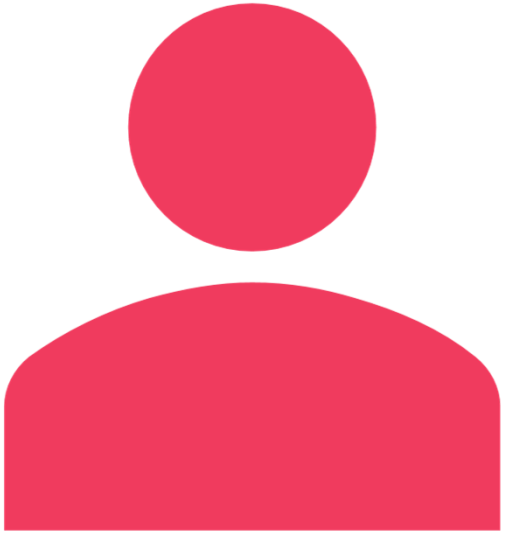
Interests and biases of paediatricians

? Other clinicians diagnosing

e.g. geneticists, psychiatrists

Assessment is challenging, time consuming – partic. for solo clinicians; developmental teams may be under-diagnosing

A child diagnosed with FASD in Australia is most likely:



Male

8 years old

In foster/adoptive care

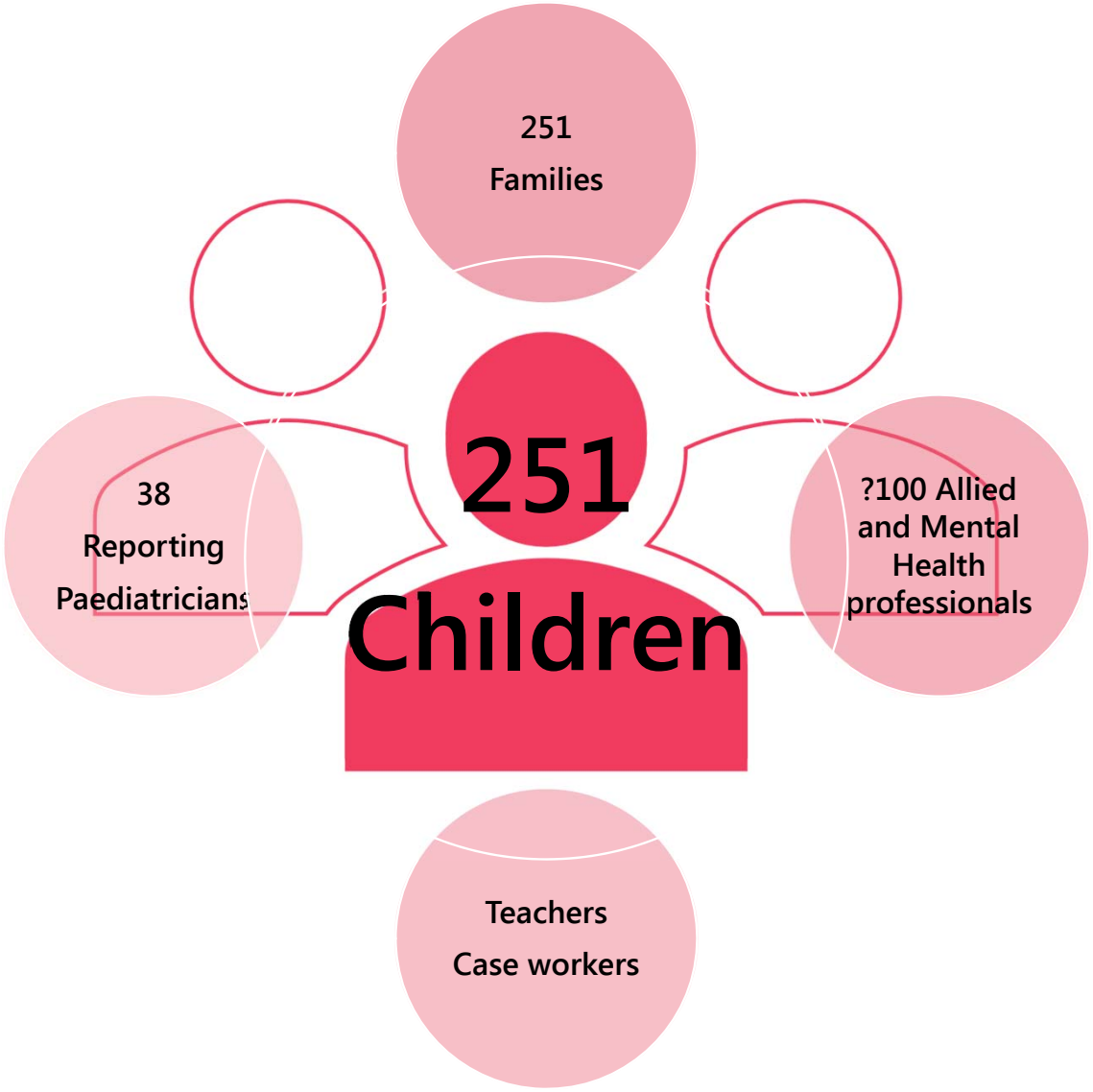
Indigenous

To have:

- <3 sentinel facial features
- A history of nicotine/polydrug co-exposure

To be diagnosed in:

- A specialist FASD clinic
- WA, NSW, or QLD



The lived experience of this study

Key trends

FASD diagnosis by Australian paediatricians is *increasing* coinciding with:

- Establishment of specialised FASD diagnostic clinics
- Availability of national diagnostic guidelines
- Likely reflects better recognition of the FASD spectrum (neurodevelop. impairment in the absence of facial and other physical features) – *the changing face of FASD*

Interpretation of key trends

FASD is likely *underdiagnosed* given:

High rates of drinking in pregnancy in Australia (40-60%)*

FASD prevalence internationally (0.8%+)**

Over-representation of children in out-of-home care and Indigenous children suggests *underdiagnosis* in:

Non-Indigenous children

Children living with their birth mother,

**Muggli E et al. "Did you ever drink more?" A detailed description of pregnant women's drinking patterns. BMC Public Health. 2016 Aug 2;16:683.*

***Lange S et al. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis. JAMA Pediatr. 2017 Oct 1;171(10):948-956*

Limitations & challenges

Reporting:	Predominance of cases from small group of reporters
	Variation in use of standardised tools could affect diagnosis: e.g for facial features
Data gaps:	Diagnostic details: eg. psychometric test scores
	Number of care placements, early life trauma, neglect/abuse
	Children's strengths

Strengths

Novel national/international data set

Able to monitor diagnostic trends

Platform for national registry

Guides service provision, planning, policy & advocacy

Educative process for paeds re: FASD

Disruptive conversations

About who we are, or are not diagnosing, and why

About FASD as form of brain injury and reframing our understanding of children accordingly

About FASD as a common <u>preventable</u> neurodevelopmental disorder/disability, *and opportunities for prevention (e.g. in future siblings) as well as better and early intervention*

About the impact of alcohol on children in our society more broadly, in all rather than just some communities

FASD is not an Indigenous problem

And it doesn't just occur in foster children

About understandable barriers, concerns, uncertainties and challenges with diagnosing FASD

As the face of FASD changes, so does the work of paediatricians.

A disruptive conversation, for a healthier future.....

The onus is on us from a public health and ethical perspective to move the conversation forward, for the kids and families we are working for now, and those yet to be born...

– *for a healthier future*

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Thank you

..and please diagnose & report FASD!

Questions ?