FETAL ALCOHOL SPECTRUM DISORDERS (FASD) IN AUSTRALIA:

PROVISIONAL FINDINGS OF NATIONAL CASE SURVEILLANCE

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What do we know?

FASD epidemiology in Australia is poorly known

APSU study of Fetal Alcohol Syndrome (FAS) / Partial FAS (PFAS) 2001-2004 (Elliott et al)

- FAS Incidence per annum 0.6 per 100,000 children aged <15 years
- Considered a significant underestimate

Lililwan Project , Fitzroy Valley (Fitzpatrick et al)

- FASD prevalence ~20% - population based, active case ascertainment study
- High risk community

FASD is *not* a rare disease

- US and Canadian data suggests prevalence 1-2% of the population (May 2014 2-5%)

What this study adds

Aim was to conduct the first national case surveillance study to identify cases across the *entire FASD spectrum*

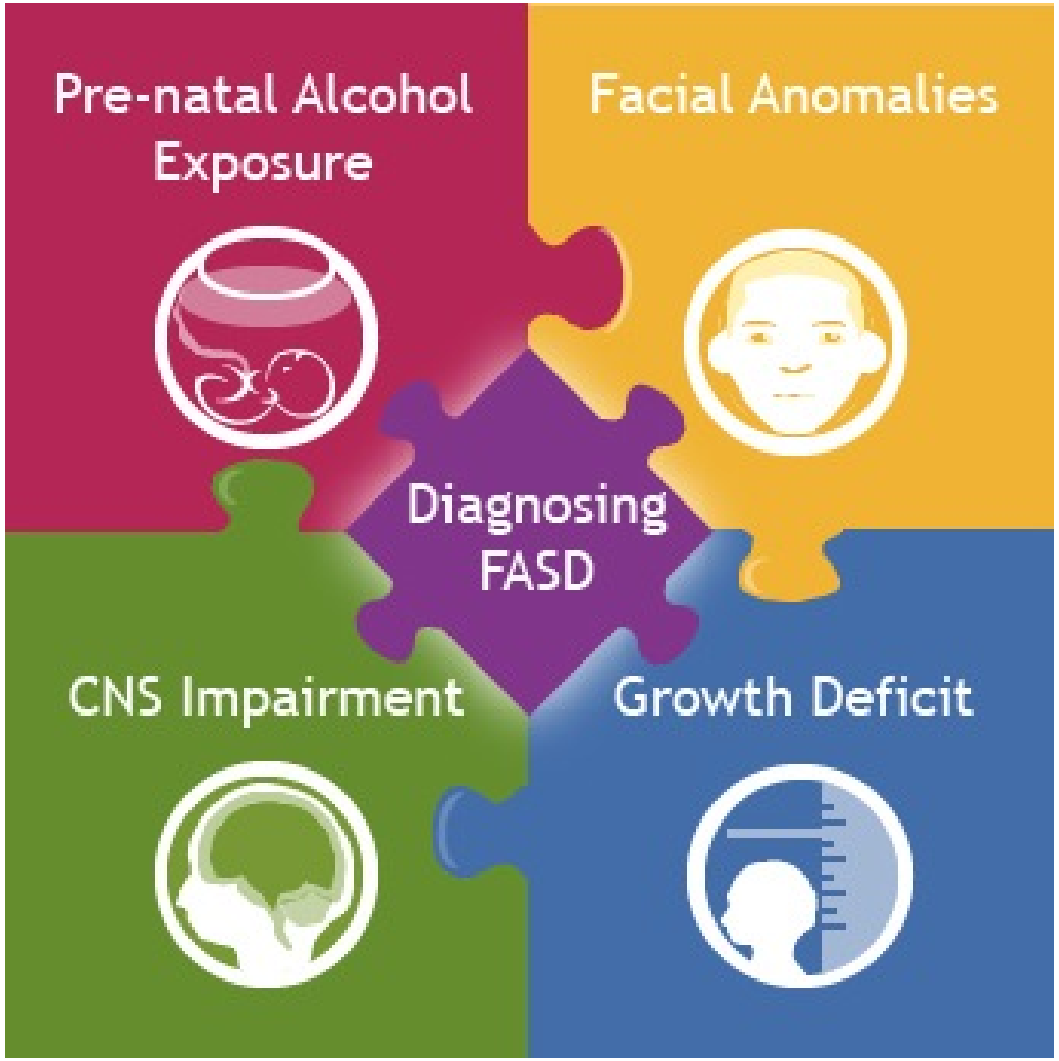
Methods

Prospective active national case-finding using monthly reporting by paediatricians to APSU

December 2014 – May 2015 (ongoing)

Children under 15

Using Australian FASD diagnostic criteria (2013)



FASD diagnostic criteria

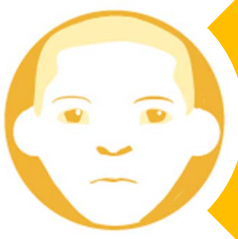
4 key aspects

Prenatal alcohol exposure

- Confirmed exposure

CNS impairment (neurodevelopment)

- Structural – microcephaly (HC <3rd %le) and/*or*
- Functional – 3 domains significantly impaired <3rd %le
  - (e.g. Cognition, Communication, ADHD, Adaptive Behaviour)



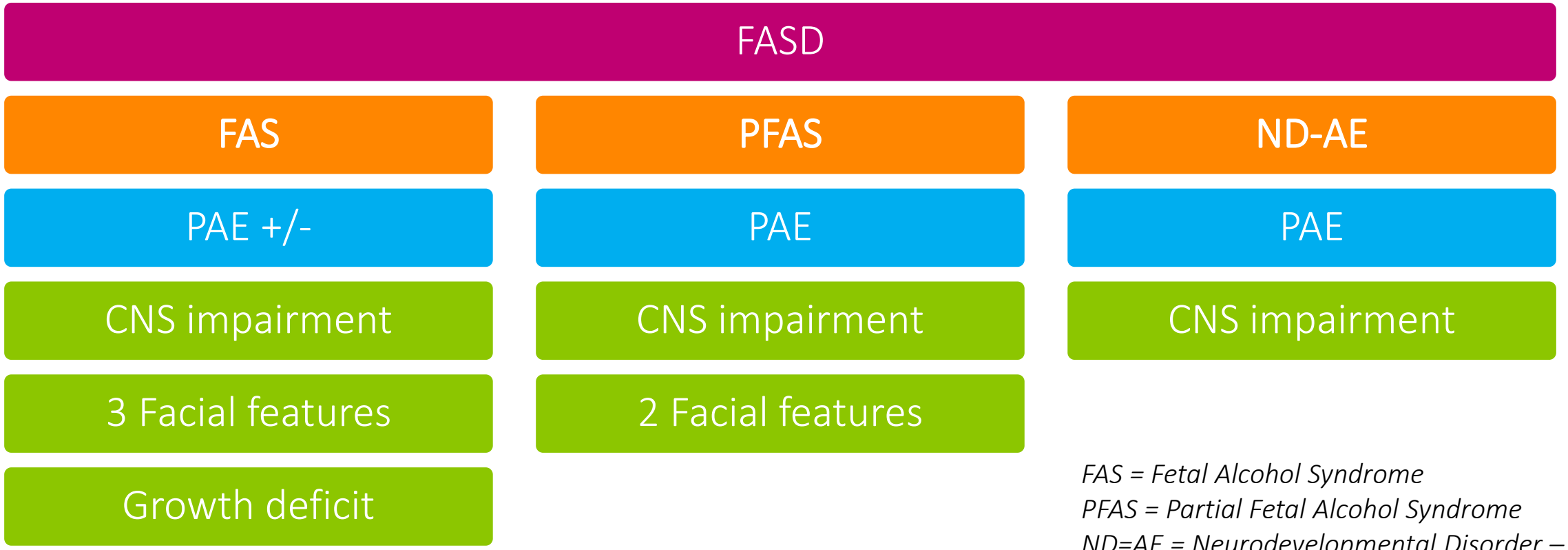
Facial features

- Palpebral fissure length (PFL) - <3rd %le
- Smooth philtrum – Rank 4 or 5 on UW Lip-Philtrum guides
- Thin upper lip - Rank 4 or 5 on UW Lip-Philtrum guides

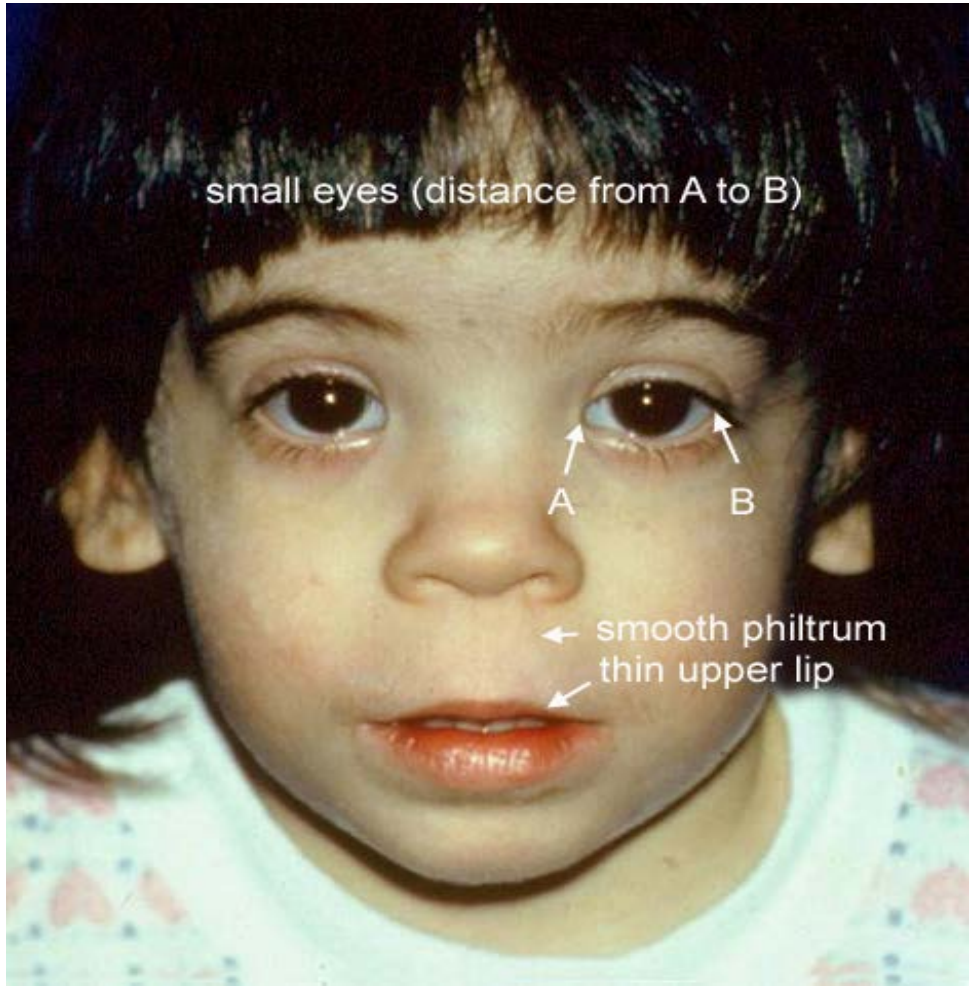
Growth deficit

- Height or weight <10th %le

Diagnostic categories



FAS = Fetal Alcohol Syndrome
PFAS = Partial Fetal Alcohol Syndrome
ND=AE = Neurodevelopmental Disorder – Alcohol Exposed
PAE = prenatal alcohol exposure



Diagnostic facial features

Facial features of FASD

Not associated with prenatal alcohol exposure, **below diagnostic threshold for FASD**

Frontal view ¾ view

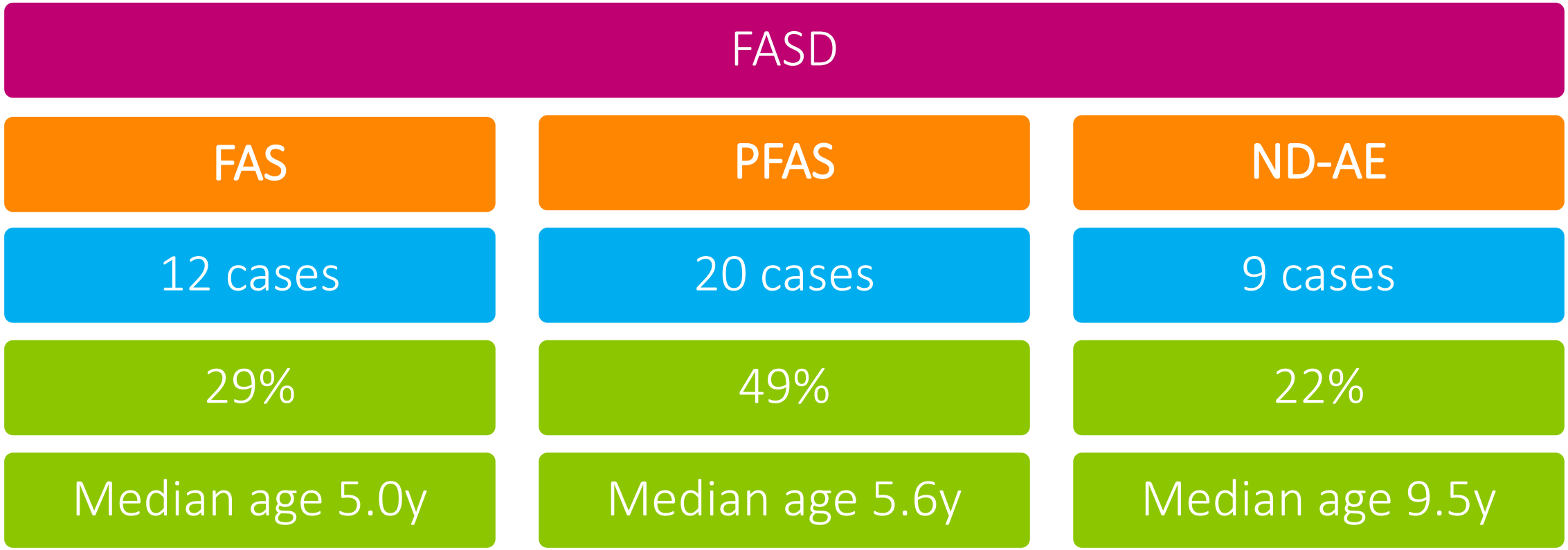
Lip-philtrum guides

University of Washington

Notifications and confirmed reports

- Duplicates n=9
- Criteria not met n=8

Results - confirmed cases

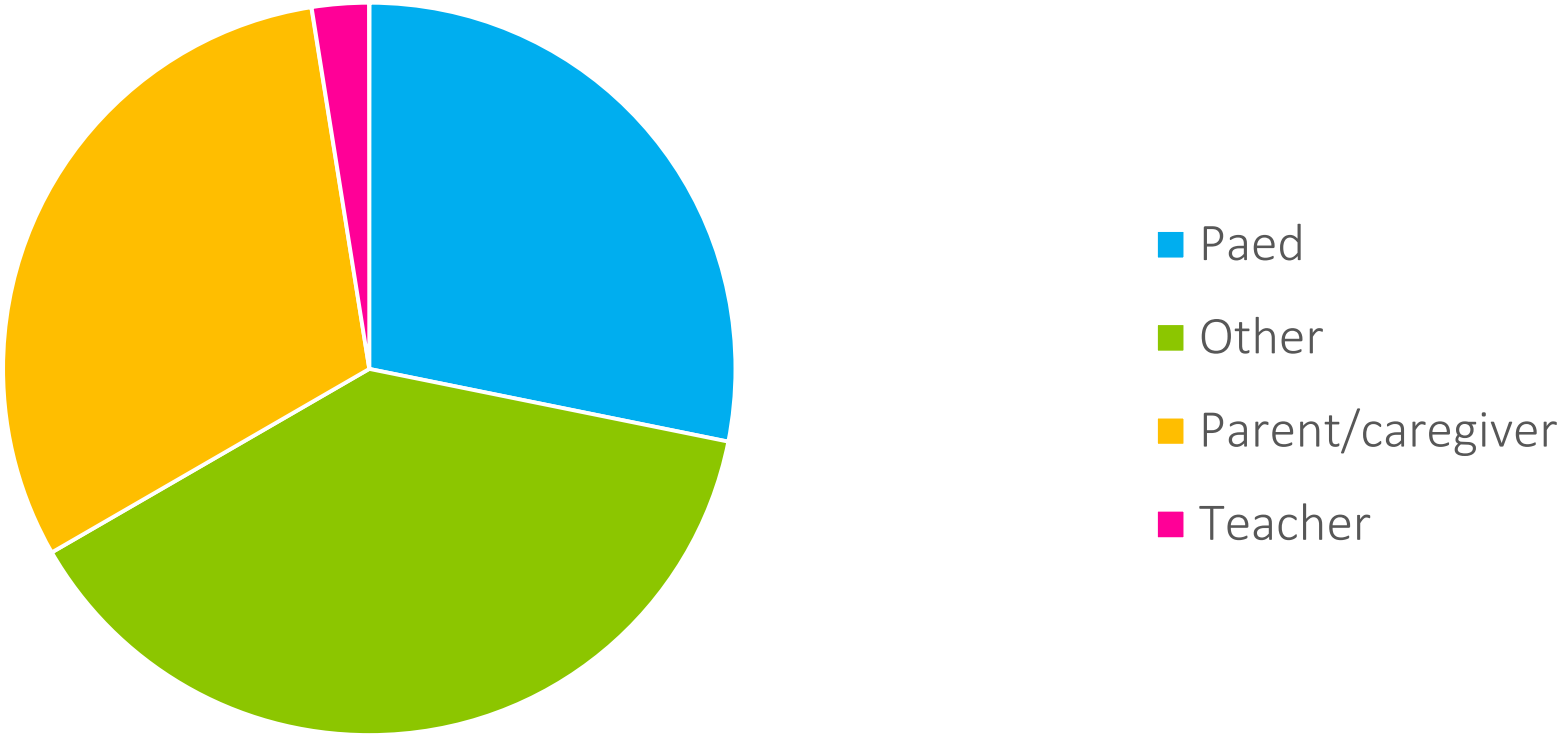


>50% from the 3 specialised FASD clinics

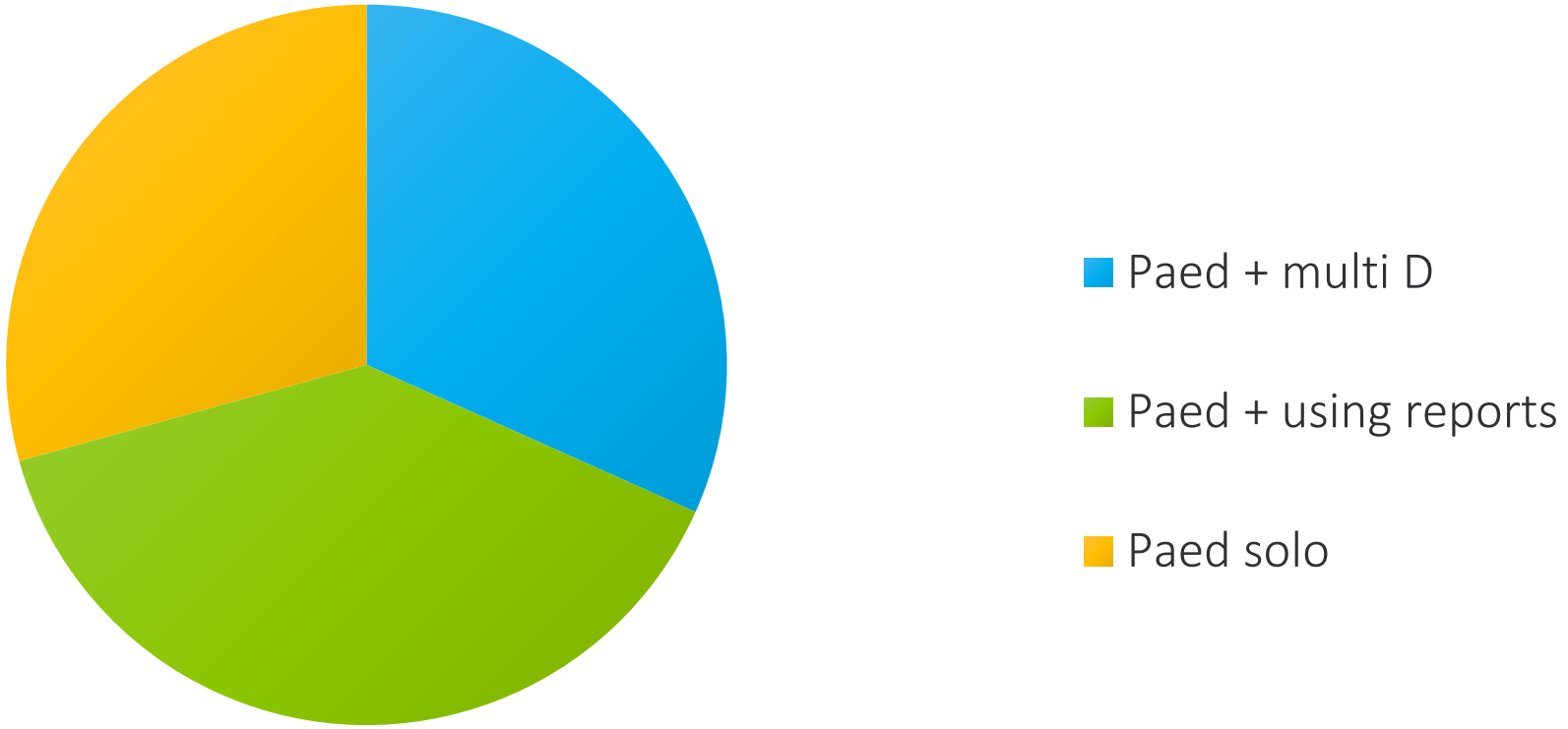
Demographics

	FASD 2014-16	FAS 2001-04
Age at diagnosis (median)	6.3y	3y
Male:female ratio	2:1	1:1
Child protection services (current/past)	73.2%	67.4%
Out of home care (foster/adoptive)	61.0%	38.0%
Biological parents' care	22.0%	40.2%
Grandparents' care	12.2%	20.7%
Sibling with FASD	19.5%	51.0%
Indigenous	41.5%	65.0%

Who first suspected FASD?



Who made diagnosis?



Prenatal alcohol exposure

Standardised approach to asking about alcohol allows for assessment of exposure risk

12 cases (29%) a standardised tool was used (i.e. AUDIT-C)

High risk exposure

Nearly 50% >7 std drinks per week

Nearly 40% 5 or more std drinks on a single occasion

Risk unknown in ~40%

Central nervous system - structural

48.8% had microcephaly

(47.9% FAS 2001-04 study)

CNS Impairment - functional

Domain	Impairment (%)	Standardised testing (%)
ADHD	48.8	29.3
Cognition	46.3	61.0
Communication	41.5	51.2
Adaptive Function	36.6	31.7
Exec Function	12.2	24.4
Memory	9.8	14.6
Global dev delay <5yo	39	

Facial features

80.5% had a *smooth philtrum*

65.9% had a *thin upper lip*

61.0% had *short palpebral fissure length*

Facial features - assessment

Assessment method (can be multiple)	%
Direct PFL measurement ruler	56.1
Lip-philtrum guide	46.3
Facial photo analysis	56.1
Visual/gestalt	78

Genetics

70.7% (n=29) had chromosomal microarray testing

- 19 normal
- 4 variants - *not clinically significant*

Other drug exposures (all cases)

	FASD 2014-16 (%)	FAS 2001-04 (%)
Cigarettes	43.9	67.4
Marijuana	31.7	25.0
Amphetamines	17.1	4.4
Heroin	12.2	4.3
Cocaine	4.9	3.3
Phenytoin/Valproate	4.8	
Methodone, diazepam	2.4	6.6
Opioids (?oral/IVDU)	2.4	

What are the data telling us?

Paediatricians are diagnosing across the FASD spectrum

- But underdiagnosing FASD without physical features
- Lack of awareness that FASD spectrum includes children without physical features

What are the data telling us?

Paediatricians are *not* using:

- Standardised tools to assess *prenatal alcohol exposure*
- Direct measurement or photographic analysis to determine palpebral fissure length
  - *The most objective diagnostic measure of facial feature, consistent across racial groups*
- Standardised or validated psychometric assessment tools to determine severity of CNS functional impairment

Strengths

Detailed demographic and diagnostic data for each case

Provides critical information re diagnostic patterns in Australia

Increases awareness of FASD among paediatricians

Allows comparison with previous FAS study

Will enable incidence estimation

Limitations

- Many case reports pending (from existing notifications)
- Under-reporting of cases of ND-AE
- Limited use of standardised assessment methods may affect classification
  - Prenatal alcohol exposure
  - CNS/neurodevelopmental impairment
  - Facial features

Take home messages

Need for clinician education about diagnostic criteria

National diagnostic tool will standardise approach and allow for international comparison

Importance of *asking about alcohol use in pregnancy*, including before pregnancy awareness, particularly in children presenting with neurodevelopmental disorders

Informs planning diagnostic, support and disability services

Need for high-index of suspicion children in high-risk groups (e.g. out of home care)

Children and adolescents with FASD may be hidden in all of our practices

Current diagnosis may be ADHD or ASD……*keep thinking and reporting FASD*

QUESTIONS

Thank you