

FASD in motion: Case surveillance and diagnosis in Australia in the 21st century

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Stretch break

Learning objectives

- To map changes in FASD diagnosis over time, in relation to national initiatives and changes in diagnostic criteria
- To inform discussion about national approaches to FASD diagnosis and data collection
- To generate debate regarding opportunities and limitations of specialised FASD diagnostic clinics
- To identify clinician-related barriers to FASD diagnosis

Conclusions & Relevance

There has been an increase in the diagnosis of FASD in Australia over the last decade coinciding with:

- development of specialist FASD clinics
- national diagnostic guidelines
- broadening of the FASD spectrum to include children with no sentinel facial features

Conclusions & Relevance

The increased diagnostic reporting has been primarily driven by 7 FASD expert paediatricians, suggesting significant limitations in diagnosis and/or reporting of FASD by Australian paediatricians in general.

This may reflect ongoing concerns and misconceptions about FASD diagnosis.

Conclusions & Relevance

Improving awareness of diagnostic rationale, methodology and case surveillance remains a priority, in conjunction with ongoing public health prevention measures.

Study Objectives – APSU FASD

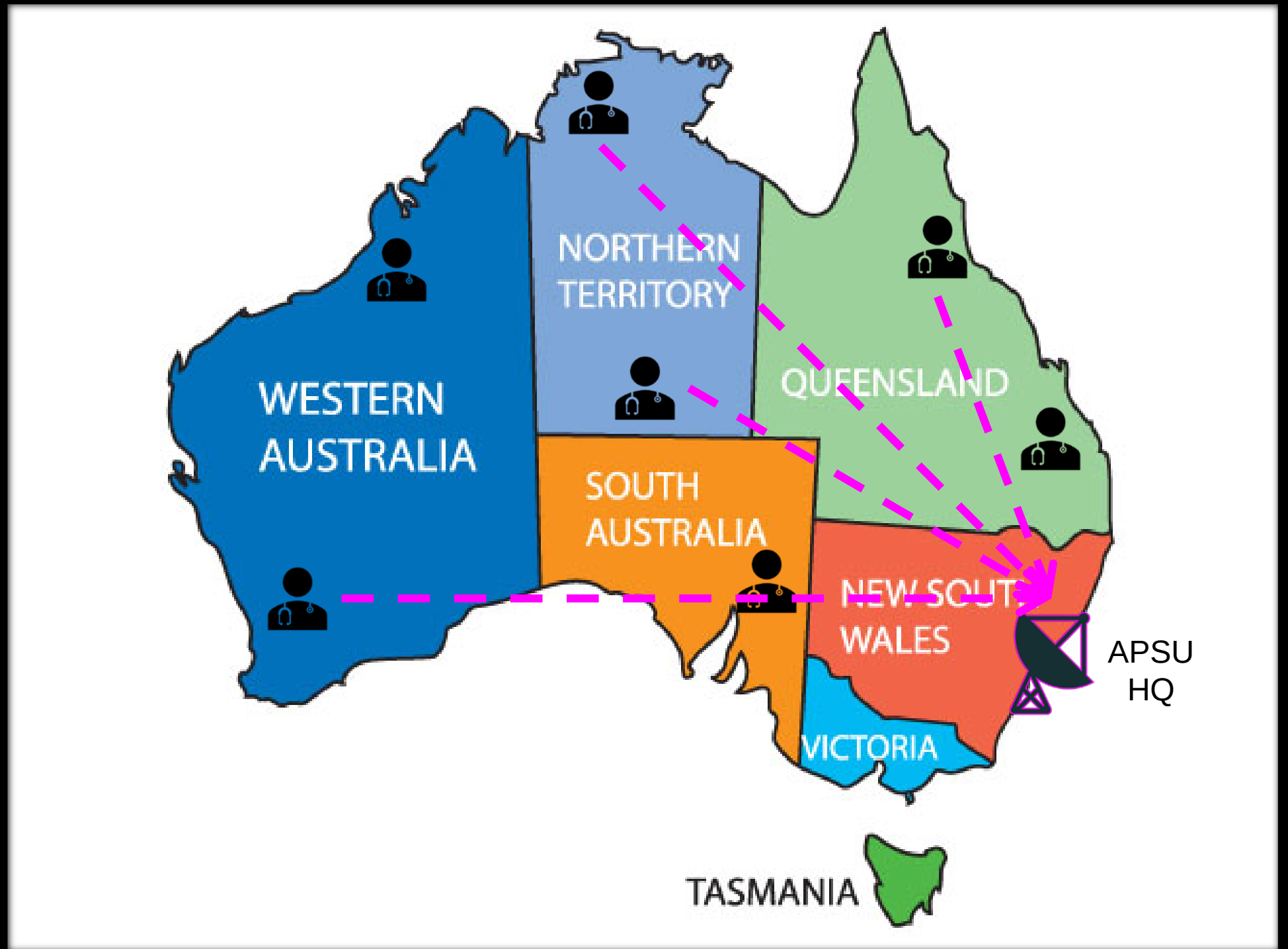
The first national data set for the entire FASD spectrum aimed to capture emerging diagnostic and demographic patterns, in order to inform:

- **Clinical practice**
- **Education**
- **Service delivery**
- **Public health initiatives**
- **Ongoing surveillance**

Data captured

- Incidence rates (new cases per year)
- Who is diagnosing FASD and where
- Demographics of children diagnosed with FASD
- Types of FASD
- Other neurodevelopmental and clinical features
- Other factors – e.g. other prenatal drug exposure
- Health service provision

What	• Prospective national case-finding • Active surveillance
When	• Jan 2015 – Dec 2017
Who	• Children and adolescents < 15 y o
How	• Paediatrician completes online case notification and then report
Case definition	• FASD +/- 3SFF (Australian guidelines)
Comparison	• To 2001-4 study


NORTHERN TERRITORY
WESTERN AUSTRALIA
QUEENSLAND
SOUTH AUSTRALIA
NEW SOUTH WALES
VICTORIA
TASMANIA
APSU HQ

Verified cases: Jan 2015-Dec 2017

Excluded n = 112

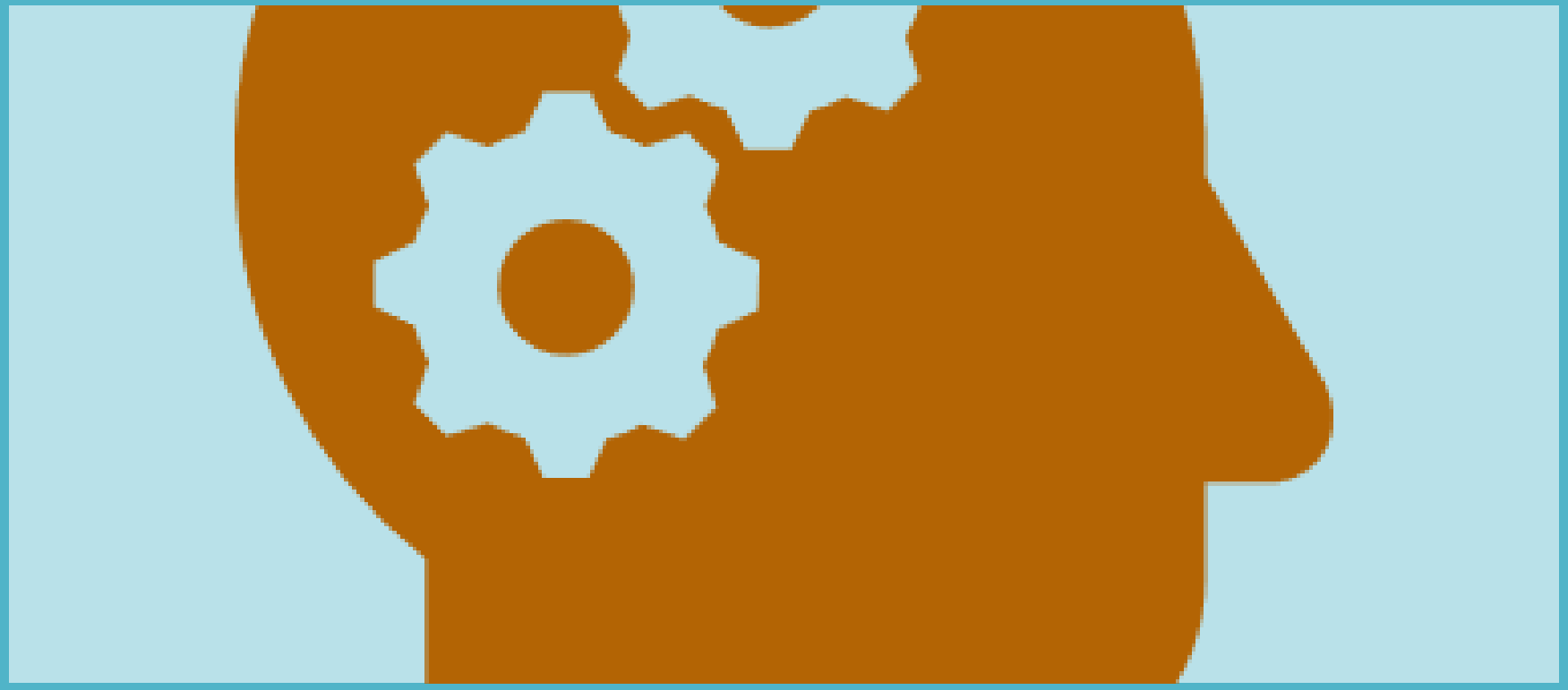
Diagnostic clinical criteria not met 16

Duplicates 41

>15 years old 32

Diagnosis outside study period 19

Incomplete records 4



FASD in motion

FASD surveillance in Australia in the 21st century

2001–2004

FAS / PFAS

Criteria: IOM 1996

FASD (+/- 3FF)

Criteria:
Australian/Canadian 2015

2015–2017

Diagnostic trends over time
Incidence *per 100,000 children <15 yo (new cases)

Diagnostic trends over time: Cases

2001-2004

92 cases over 4 years

23 Cases per year

FAS n = 25 (27%)

Suspected FAS n = 2 (2%)

PFAS n = 65 (71%)

280 Cases over 3 years

93 Cases per year

FASD + 3 SFF n = 61 (22%)

FASD < 3 SFF n = 219 (78%)

2015-2017

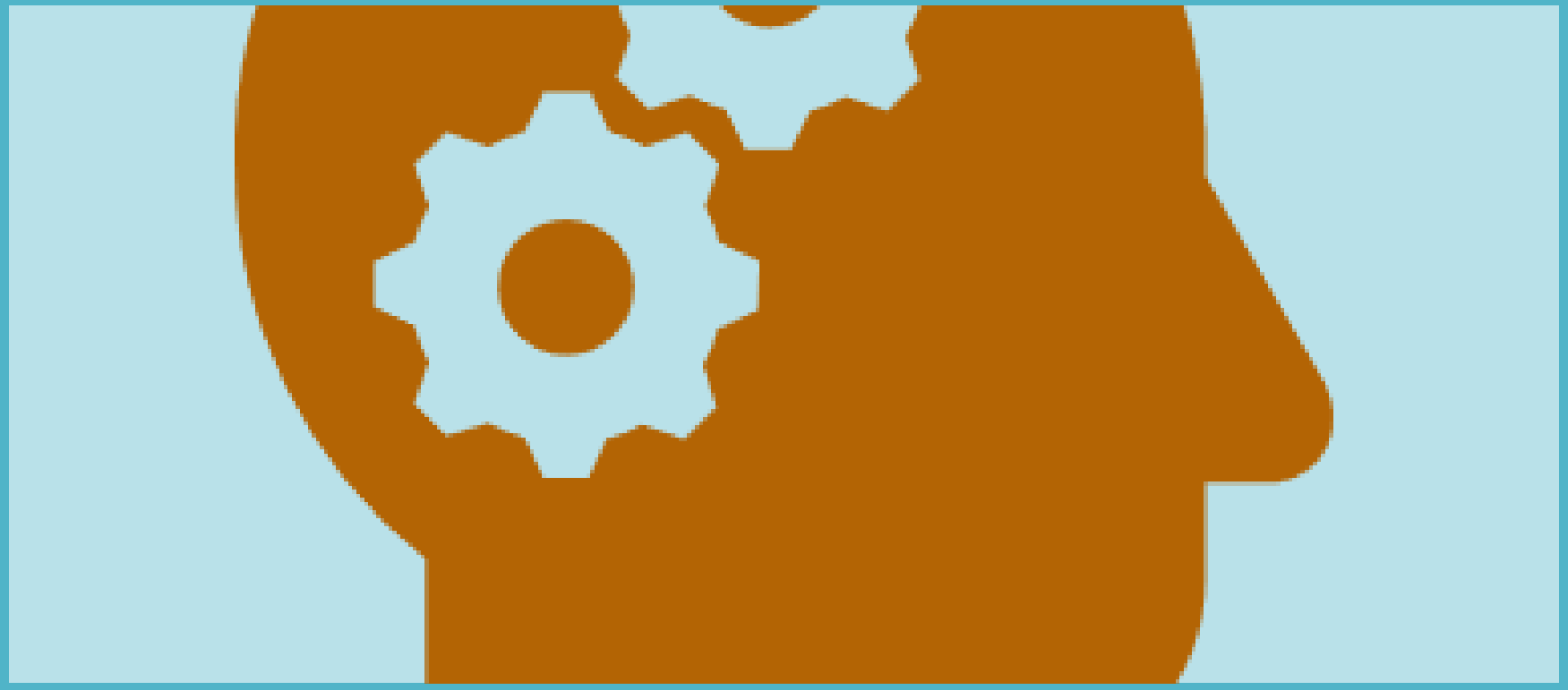
Diagnostic trends over time
Sentinel Facial Features (SFF)

2001-2004

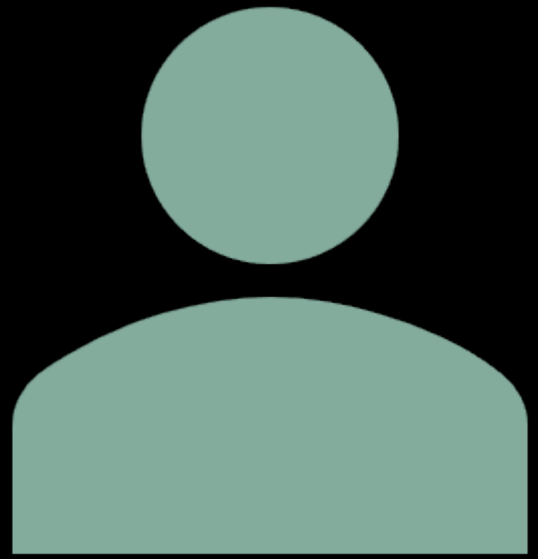
3 SFF (FAS)	9 cases per year
Ratio 3SFF:<3SFF	1:2.4
3 SFF (Total)	14 cases per year
Ratio 3SFF:<3SFF	1:1.4

3 SFF	20 cases per year
Ratio 3SFF:<3SFF	1:3.6

2015-2017



Profile of FASD diagnosis in Australia 2015-2017



A child diagnosed with FASD in 2014-7 in Australia is most likely:

To be diagnosed in:

- **A specialist FASD clinic**
- **3 states/territories** (WA, QLD, NSW)

Specialist FASD clinicians more likely to diagnose FASD <3 SFF vs +3SFF

- 82% vs 57% $p < .001$

Clinical diagnostic patterns

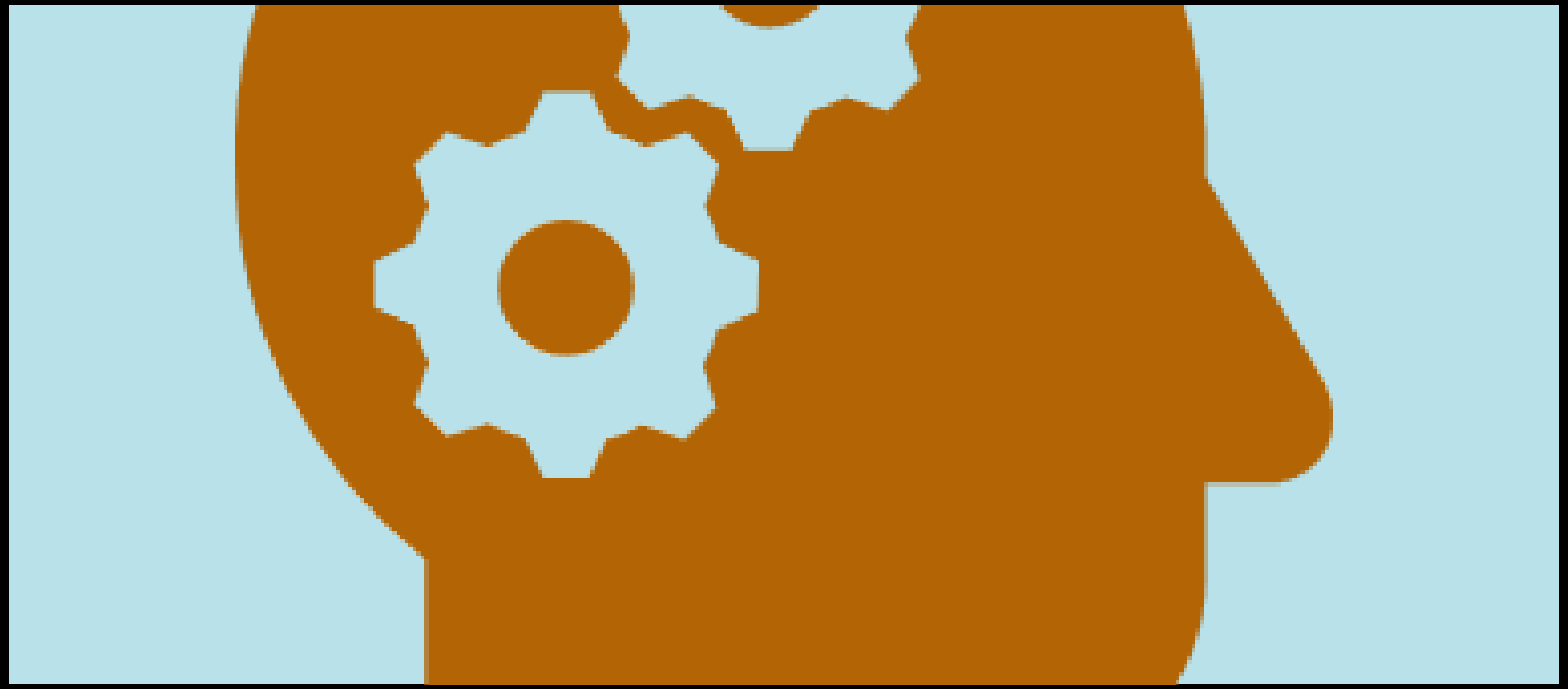
Large majority of cases diagnosed/ reported by FASD champions in multidisc. teams

- 84% by 7 paediatricians
- 49% by 1 paediatrician

Small number of paediatricians/ clinicians diagnosing/reporting FASD

- FASD (n=34) vs Total APSU (n=1500)
- reporting paediatricians/clinicians
- Paediatricians ~95%:
- (General 40-51%, Devel. 10-15%, Neonat. 10-20%)
- Clin. Geneticists 2-5%
- Child Psychiatry 1%

Who is diagnosing and reporting FASD in Australia?



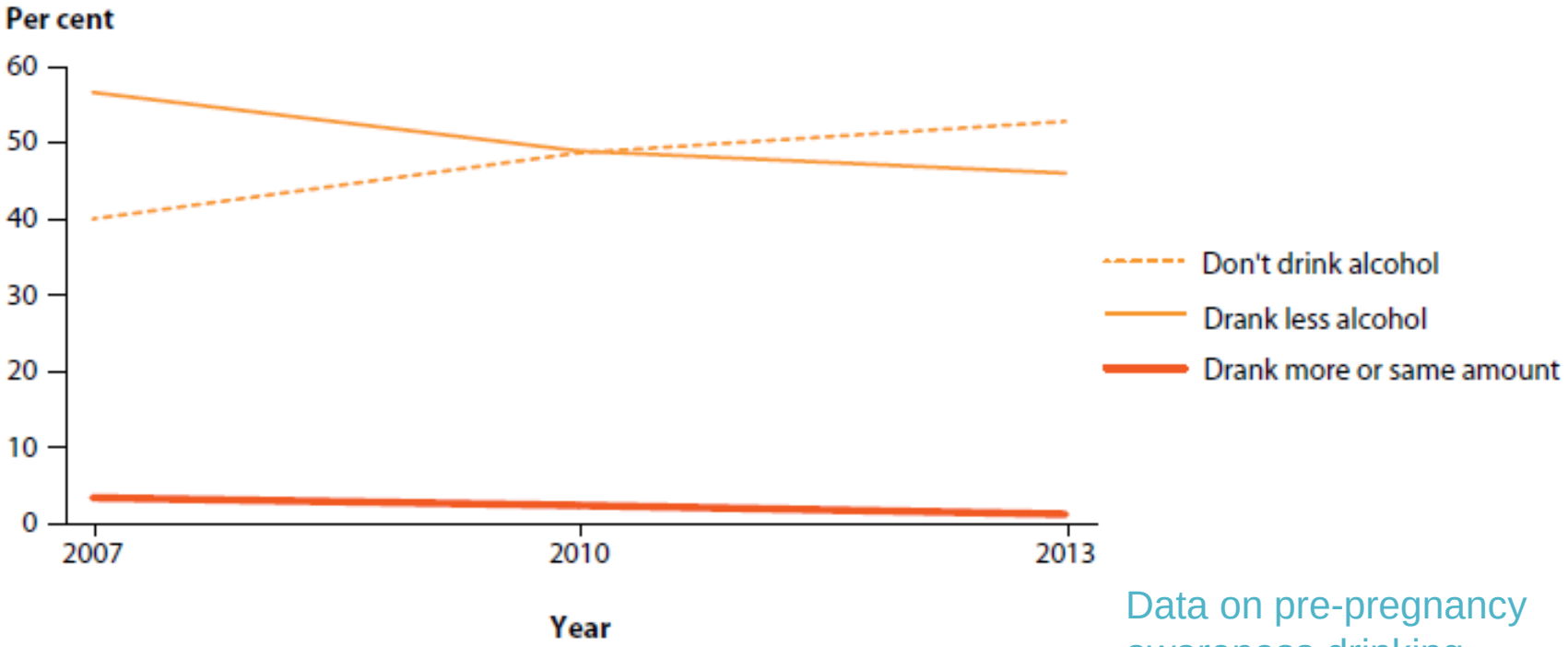
Interpretation

Paediatricians diagnosing FASD in Australia
Positive trends

Paediatricians are diagnosing and reporting FASD

Increasing rates of FASD diagnosis

Are increased rates of drinking in pregnancy a factor in increased FASD diagnosis in Australia?



Data on pre-pregnancy awareness drinking

Note: Base is only pregnant women or women pregnant and breastfeeding at the same time.

Source: Online Table 8.10.

Figure 8.10: Pregnant women who drank more, less or the same amount of alcohol compared with when they were not pregnant, pregnant women aged 14–49, 2007 to 2013 (per cent)

National Drug Strategy Household Survey detailed report 2013

Paediatricians diagnosing FASD in Australia
Positive trends

Better understanding of FASD spectrum, incl. children without physical features

Establishment of specialised FASD diagnostic clinics

Use and availability national diagnostic guidelines

Reporting mechanism in place, national registry established

Paediatricians diagnosing FASD in Australia
A work in progress

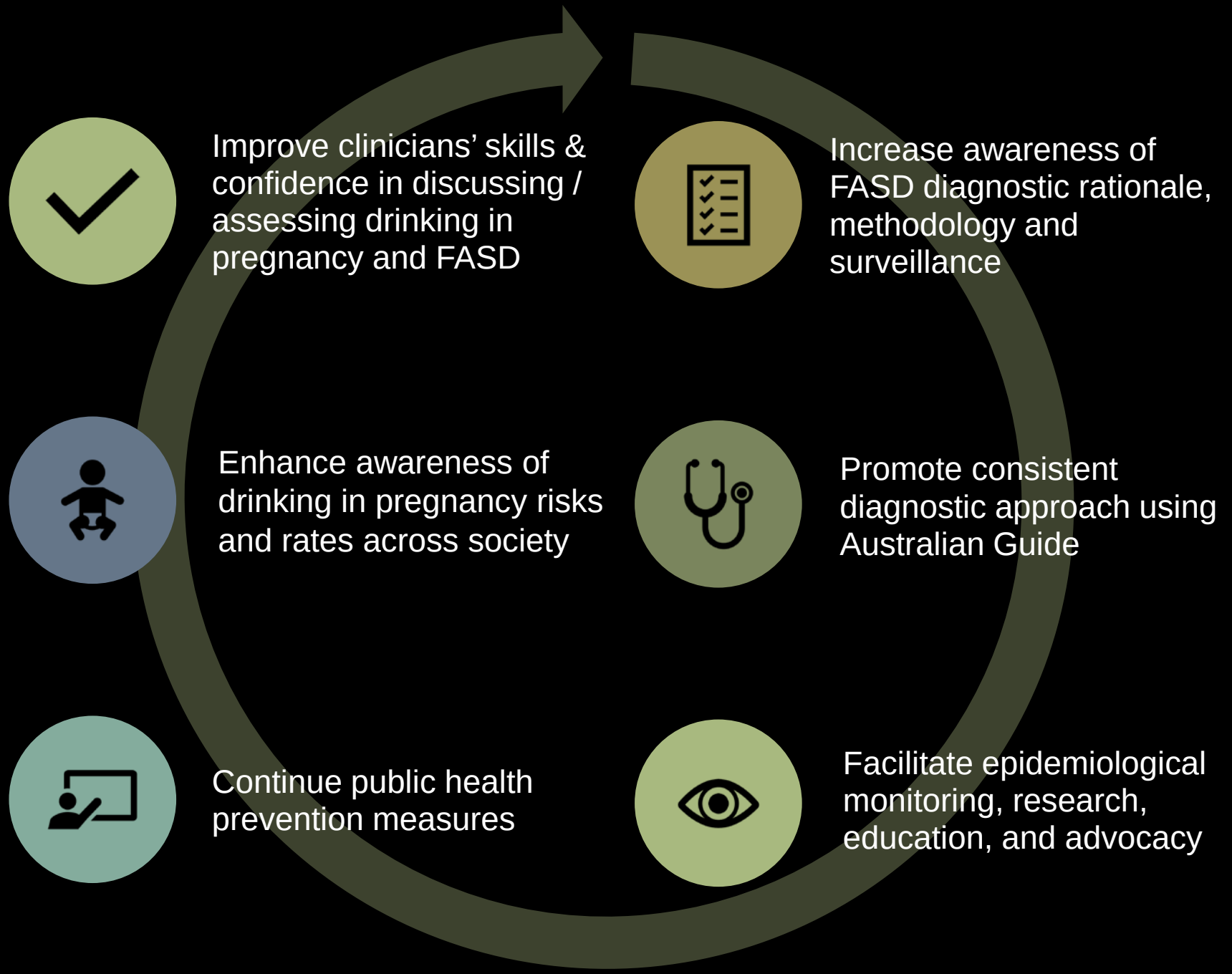
The main drive comes from a small group of FASD informed and motivated paediatricians/clinics

More paediatricians could be diagnosing/reporting FASD

There is significant variation across states, not proportional to state populations

There may be ongoing concerns and misconceptions about FASD diagnosis among paediatricians

Priorities


Improve clinicians' skills & confidence in discussing / assessing drinking in pregnancy and FASD
Increase awareness of FASD diagnostic rationale, methodology and surveillance
Enhance awareness of drinking in pregnancy risks and rates across society
Promote consistent diagnostic approach using Australian Guide
Continue public health prevention measures
Facilitate epidemiological monitoring, research, education, and advocacy

Thank you

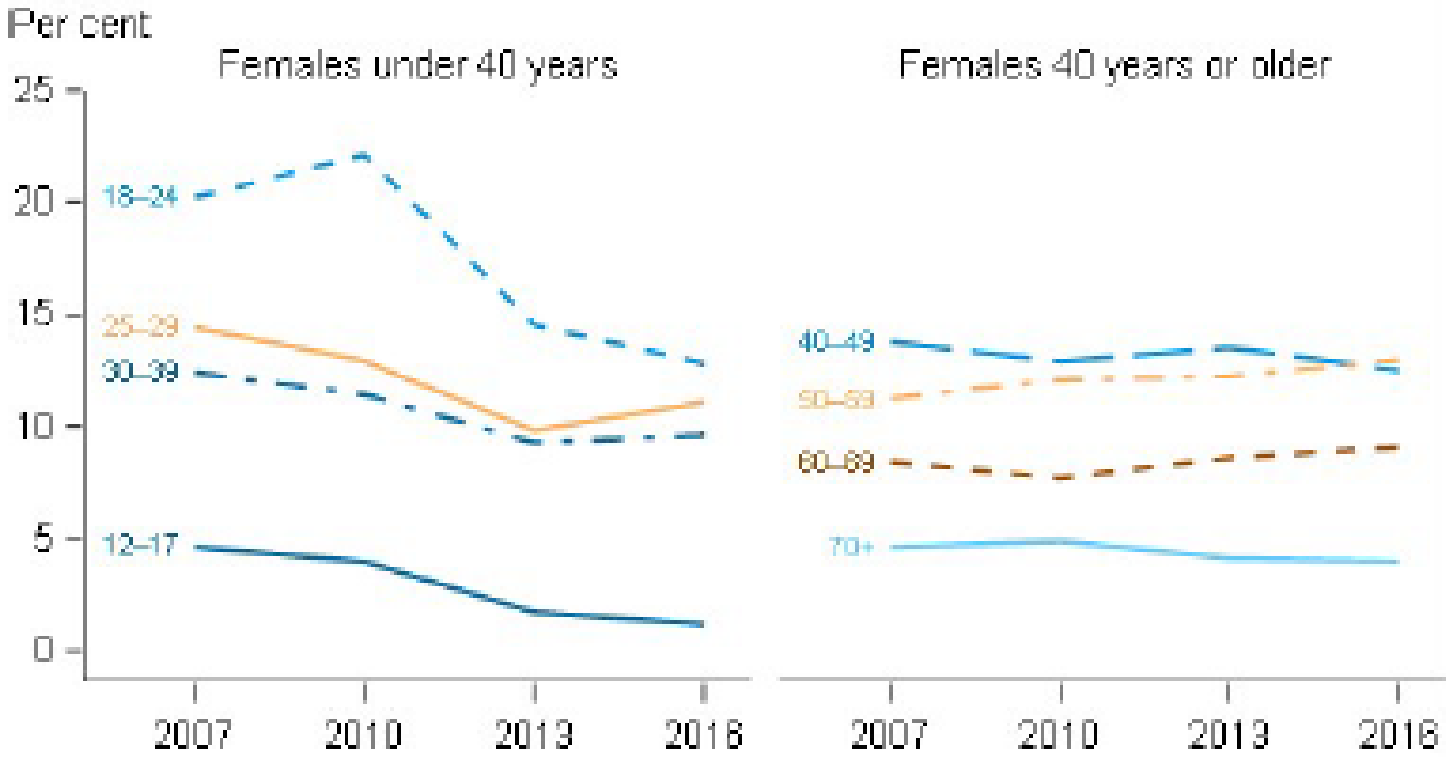
Discussion

EXTRAS

Assessment rates & methods

Prenatal alcohol exposure	**16% used standardised tool (typically AUDIT-C)** - of those, 61% had high-risk exposure (score >5)
Facial features	**Photo analysis software used in 37%** Lip-philtrum guides 80% Direct PFL measurement 73% (Stromland charts used 60%) 37% Short PFL, 54% Smooth philtrum, 45% Thin upper lip
Neurodevelopment	**Domain assessment rates varied 58-94%** **Standardised testing rates varied 48-90% between domains** (e.g. Motor Skills low, Cognition high)
Growth impairment	Reported ‘unknown’ in 56%
Genetics	Microarray 30%, karyotype in 8%, the vast majority normal.

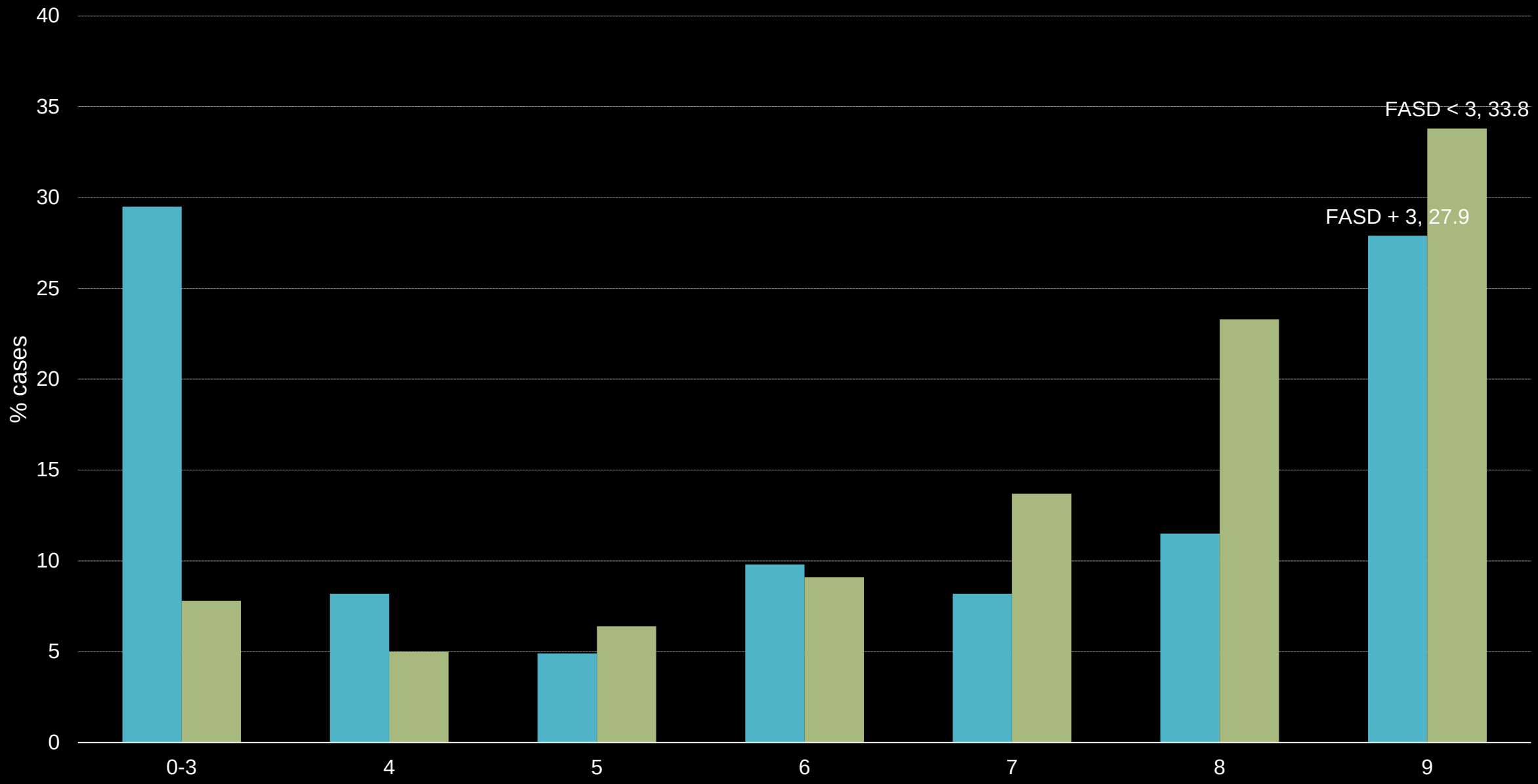
Figure 6: Proportion of females exceeding the lifetime risk guidelines[(a)], by age, 2007 to 2016 (per cent)



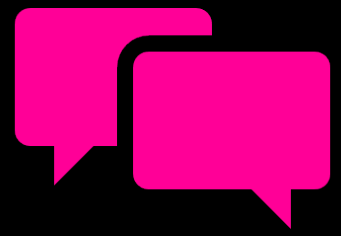
a. on average consumed more than 2 standard drinks per day

Source: NDSHS 2016 preliminary findings (Data tables).

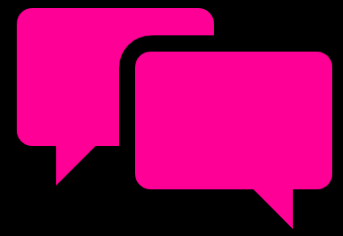
NUMBER OF NEURODEVELOPMENT DOMAINS ASSESSED



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.**

NEURODEVELOPMENTAL DOMAINS

				
Brain structure /neurology Microcephaly 23% Structural 7%	**Motor skills**	**Cognition**	**Language**	**Academic Achievement** **73%**
				
Memory	**Attention** **79%**	**Executive function, Impulse control Hyperactivity** **81%**	**Affect Regulation**	**Adaptive behaviour, Social skills, Social comm.** **73%**

Prevalence studies: community specific

Lililwan: High risk community (2015)
FASD 20% *Fitzpatrick et al*

Banksia Hill: Youth in detention (2018)
FASD 36% *Bower et al*

Incidence studies: national case surveillance

1. **APSU FAS/PFAS** (2001-2004) *Elliott et al*
2. **APSU FASD** (2015-2018)

Context: FASD epidemiology in Australia

Diagnostic patterns: State/territory variation

Possible reasons:

Drinking patterns different in different regions

Real differences in prevalence

Under vs over diagnoses

Access to diagnostic services difference

Interests and biases of paediatricians

Other clinicians diagnosing, and not reporting to APSU (e.g. geneticists, psychiatrists)