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Maternal follow-up: mechanisms to engage and retain for long term follow-up

Stephanie Brown
Healthy Mothers Healthy Families

Healthy Mothers Healthy Families

Family violence: pathways to safety and resilience

Working at the interface of policy, services & community

Aboriginal children and families

Children and families of refugee background

Health, well-being and equity for all mothers, children and families

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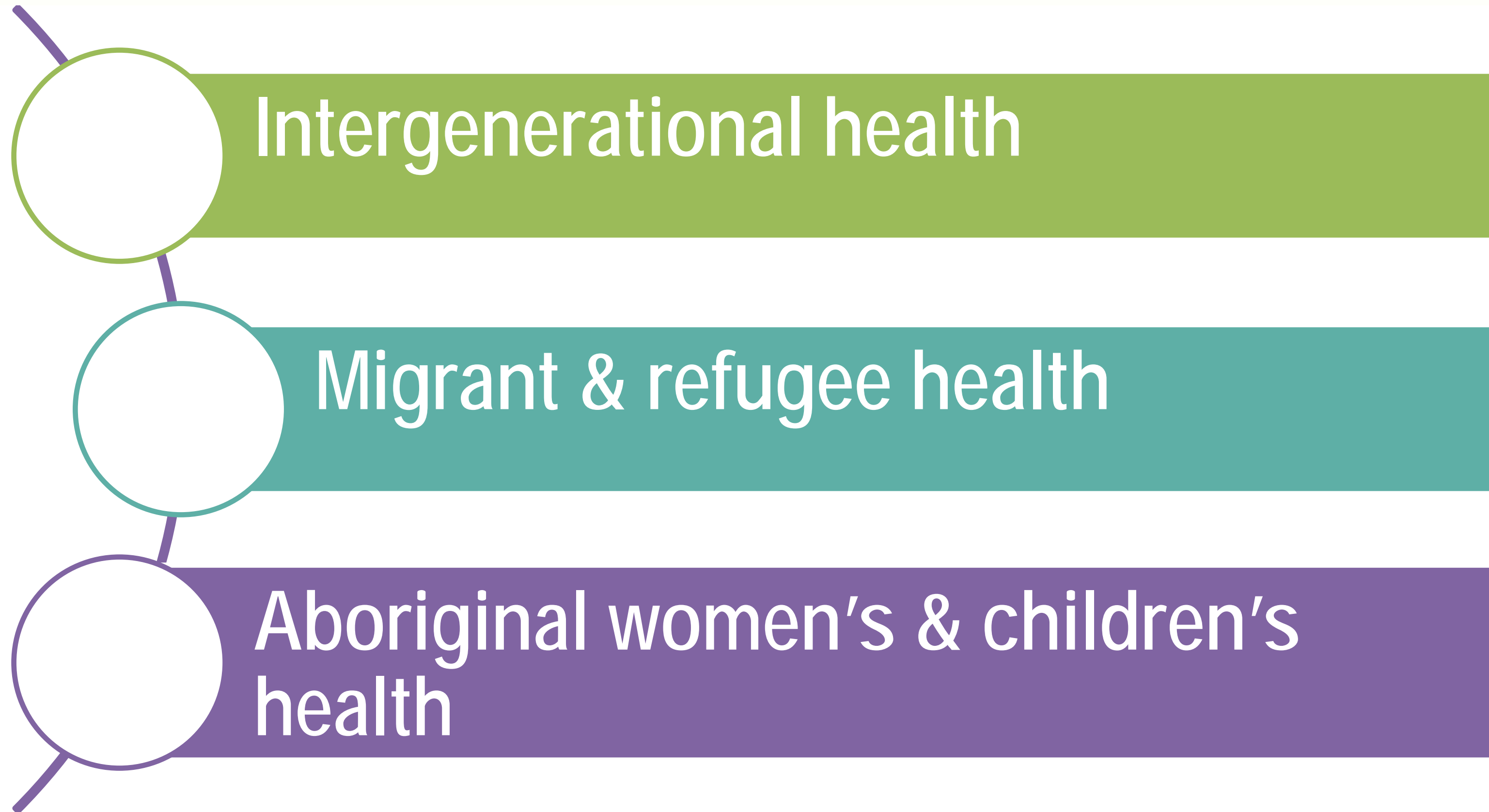

maternal health study

Aboriginal families STUDY

BRIDGINGTHEGAP
PARTNERSHIPS FOR CHANGE IN REFUGEE CHILD & FAMILY HEALTH

the CHILDHOOD RESILIENCE study
Understanding how children grow up strong

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Purpose in this session

- Focus on mothers
- Mechanisms to engage & retain mothers in long term follow-up

What does the evidence say?

- Treweek S et al, Strategies to improve recruitment to RCTs. Cochrane Database Syst Rev 2010
- Brueton VC et al, Strategies to improve retention in randomised trials. Cochrane Database Syst Rev 2013
- Booker C et al. A systematic review of the effect of retention methods in population-based cohort studies. BMC Public Health 2011

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What works?

- Financial incentives
- Financial incentives of increasing value
- Reminder letters
- Repeat questionnaires
- Offering alternative locations for face-to-face follow up

Limitations of the evidence?

- Few studies take a systematic approach to evaluation of engagement and retention strategies
- Not clear what works for whom or in what context
- What works for child follow up may not work for maternal follow up

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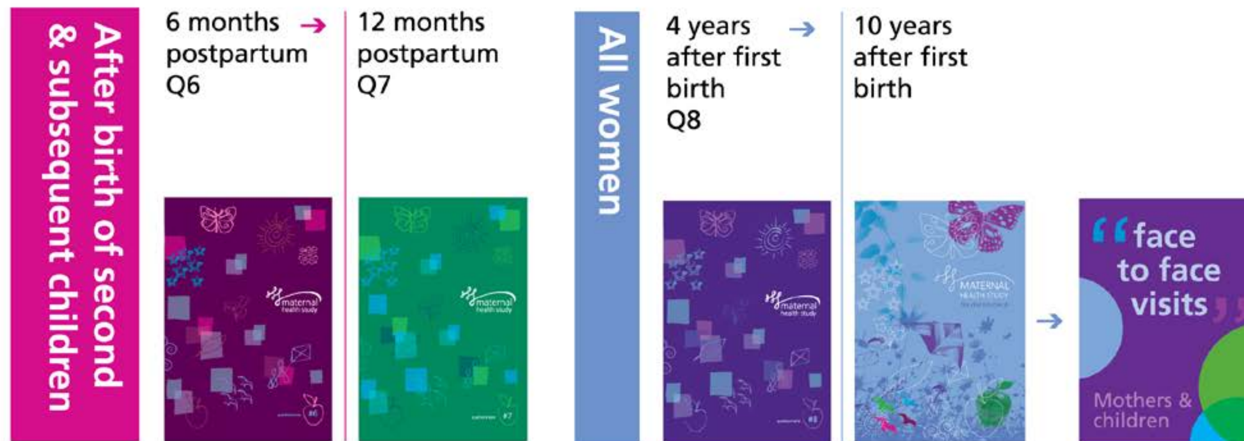
Prospective pregnancy cohort 1500 first time mothers



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Participant retention

STAGE ONE

- 98% at 32 weeks (CATI)
- 95% at 3 months (Q)
- 93% at 6 months
- 92% at 9 months (CATI)
- 90% at 12 months (Q)
- 88% at 18 months (Q)

STAGE TWO

- 83% at 4 years (Q)

STAGE THREE

- 83% at 10 years (Q)
- 67% at 11 years (site or home visit)

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What we did (1)

- Purpose designed tracking data base
- Pre-tested questionnaires and interview schedules
- Postal and telephone reminders
- Newsletters x 2 per annum
- Follow-up via alternate contacts (when mail returned to sender, phone numbers disconnected)

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What we did (2)

- Letters signed by investigators
- Responded by mail or phone to participant comments on questionnaires
- CATI interviews x 2 in first 12 months
- From 18 months - 6 monthly phone call to update contact details & identify 2nd and subsequent births

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What we didn't do ...

- Financial incentives (until 10 year face-to-face follow-up)
- Offer on-line questionnaire option (until 10 year follow-up)
- Strategies to engage 'hard to reach' populations (e.g. younger women, women of refugee background, Aboriginal women)

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Differential attrition

- Younger women
- Women of non-English speaking background
- Women experiencing social adversity/stress
- Women exposed to intimate partner violence

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What would you do?

Engaging & retaining 'harder to reach' populations

- What makes some populations harder to reach than others?
- What can we do about it?

What we are doing now

- Partnerships with community organisations:
    - Aboriginal Health Council of South Australia
    - Victorian Foundation for Survivors of Torture
- Building capability for working with Aboriginal and refugee communities

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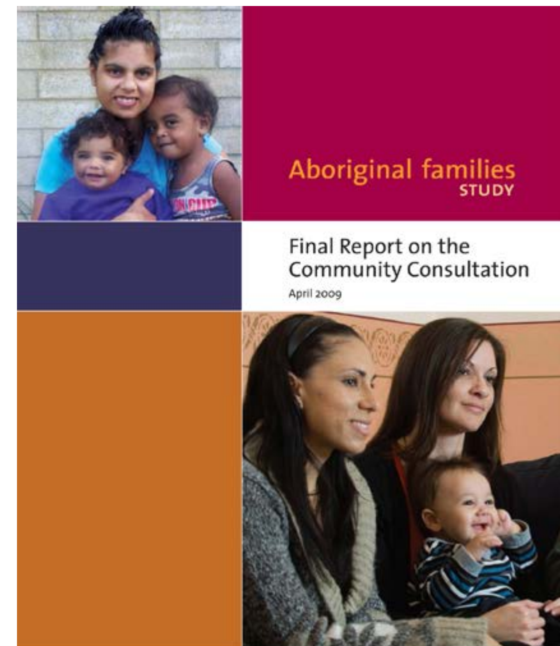
- Partnership with AHCSA
- Statewide consultations with Aboriginal communities in SA



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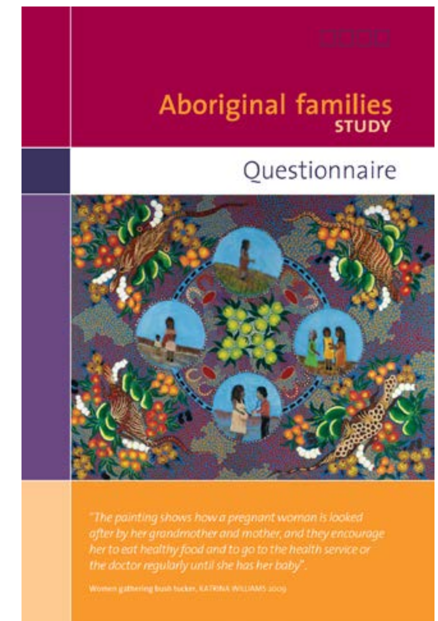
- AFS Aboriginal Advisory Group 2007-
- Pilot study 2010
- Main study 2011-2013, funded by NHMRC



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What we did

- Structured questionnaire
- Study designed measures
- Team of 12 Aboriginal interviewers

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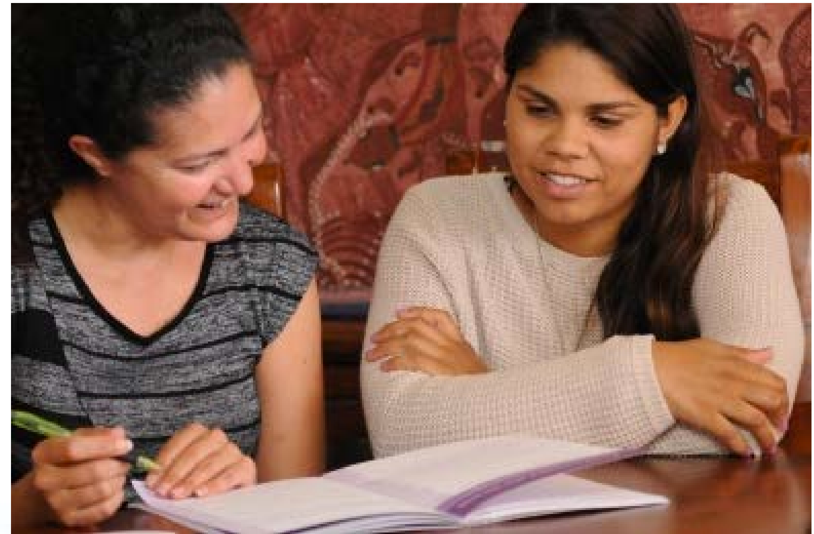
Sample

- 344 women took part
- Around a quarter of Aboriginal women who gave birth in SA over a two year period



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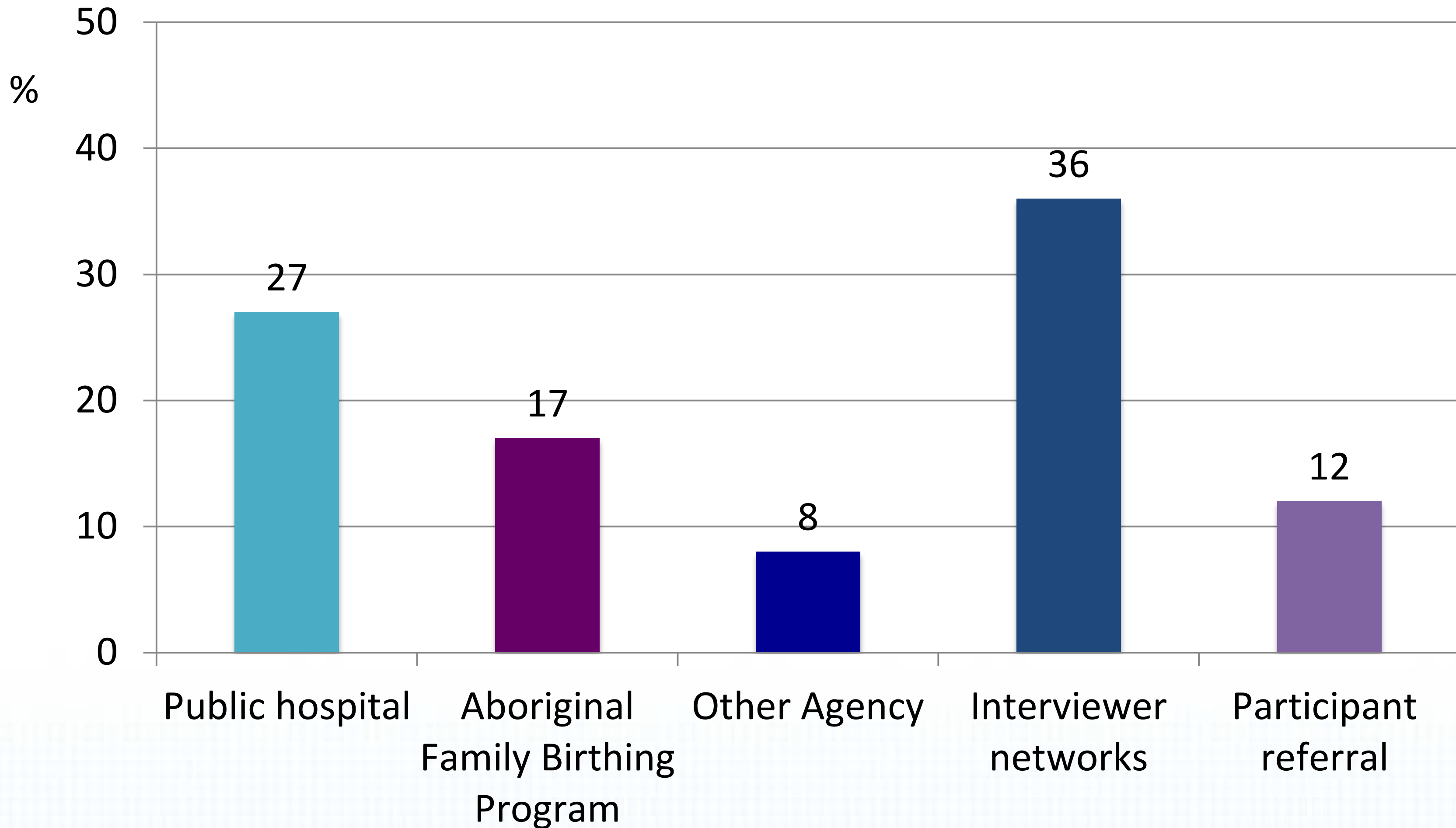
Sources of recruitment



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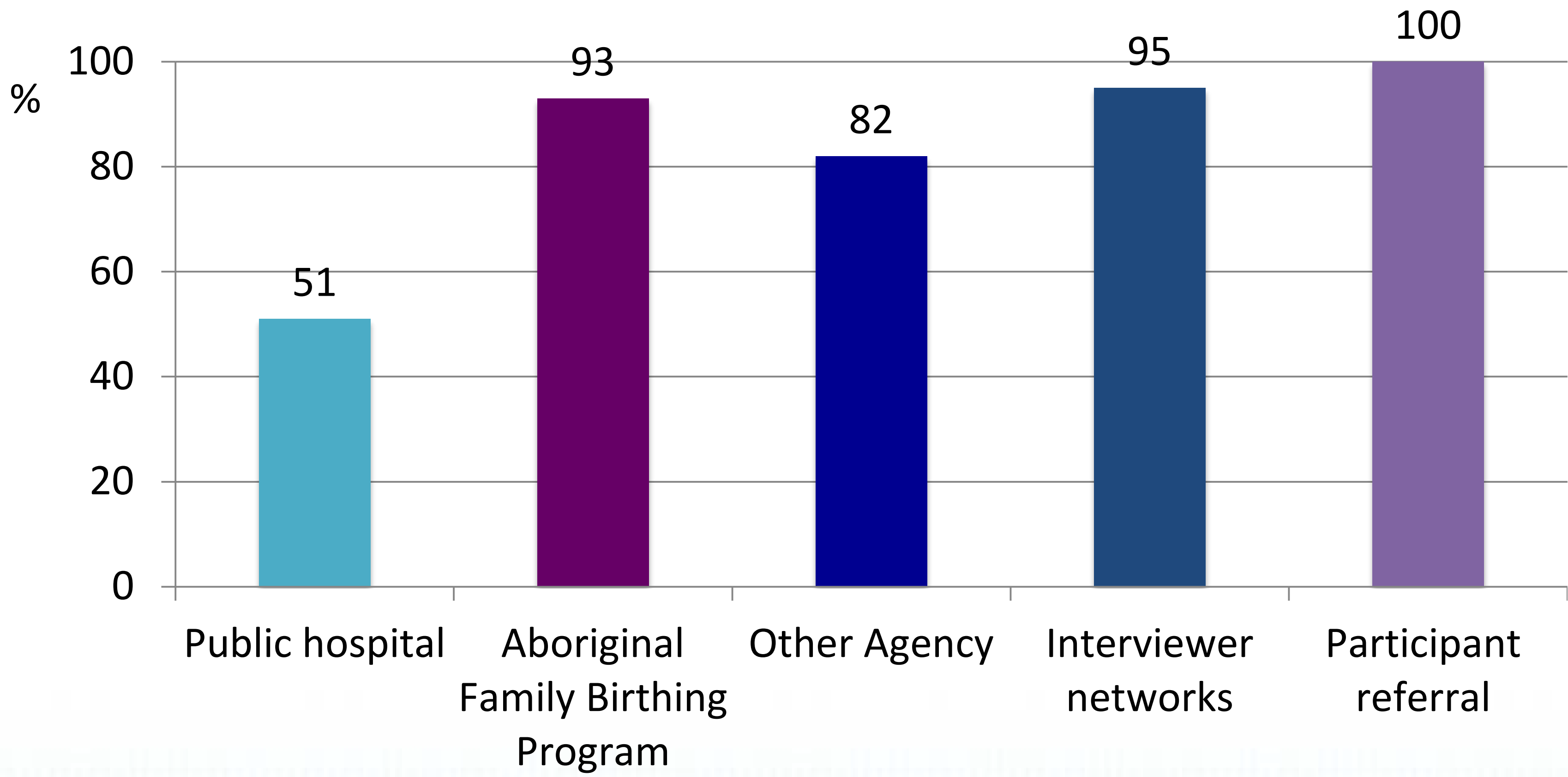
Completed questionnaire



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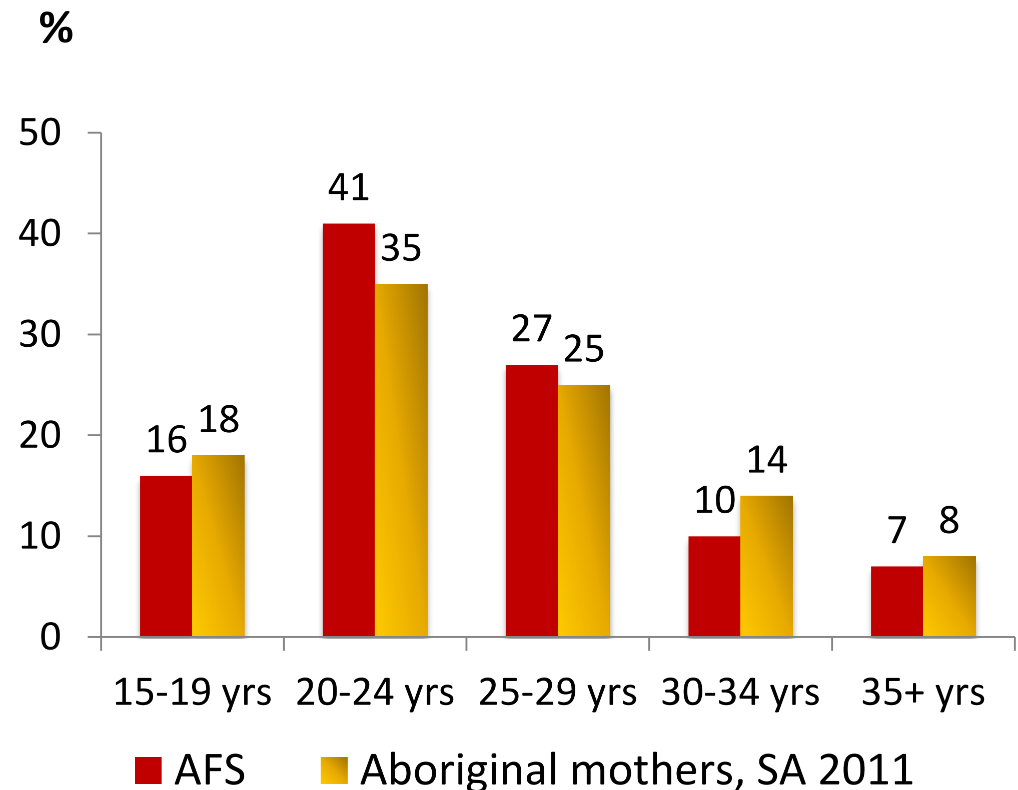
How representative was the sample?

- Younger women were well represented



What we did differently ….

- Community consultation informed research questions and study methods:
  - structured questionnaire
  - inclusive of young women (14-17 years)
  - stressful events, social health issues, cannabis use
- Extensive pre-testing of questionnaire:
  - wording of questions
  - sequence of questions
  - preambles/explanations
  - option: ‘prefer not to answer’
  - omitted some items (e.g. income, relationship status)

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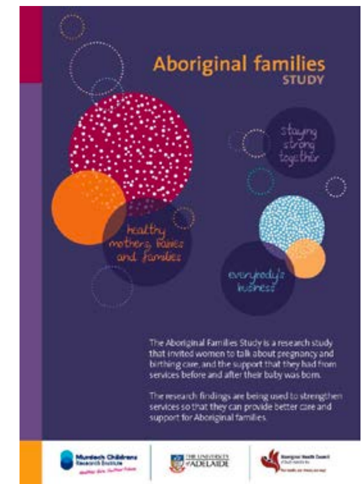
What we did differently ….

- Consent procedure for younger women (14-17 years, without parent/guardian consent)
- Option of oral consent
- Option of interview or self-complete
- Ongoing community engagement and feedback



Key messages …

- ‘Hard to reach’ does not mean ‘impossible to reach’
- Apply same rigour to the way that we engage with study participants, that we apply to evaluation of clinical interventions