



# **Engaging women who have had a stillbirth to participate in research**

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# A Significant Bereavement

For families the death of an infant is among one of the most stressful life events an adult may experience

Also staff - “...nearly one in 10 obstetricians reported they had considered giving up obstetric practice because of the emotional difficulty in caring for a patient with a stillbirth”

Fish, W., *Differences in grief intensity in bereaved parents* 1986, Champaign, IL: Research Press Co.

Gold, K.J., I. Leon, and M.C. Chames, *National survey of obstetrician attitudes about timing the subsequent pregnancy after perinatal death*. American Journal of Obstetrics & Gynecology, 2010. **202**(4): p. 357.e1-6.



“Almost no burden affecting families is so big and yet so invisible both in society and on the global public health agenda.”

**Joy Lawn, M.D., PhD, Director of Global Evidence and Policy, Saving Newborn Lives/Save the Children and a lead author of The Lancet’s Stillbirths Series**

# The Evidence

Few empirical studies examining the responses of bereaved individuals to participation in research.

- Focus includes:
  - Loss of parent, spouse or other family member
  - Loss of child or family member due to cancer
  - Loss of child through SIDS, suicides or accidents
  - Loss of child through chronic progressive condition
- Bereavement outcomes not attitudes to research
- No controls
- Majority - positive response as a result of their involvement.

# The Presumptions



**LAURA SMITH**  
*Freelance writer for the  
likes of The Guardian,  
The Independent and  
Marie Claire*

**“Stillbirth** is perhaps the biggest taboo. Literally nobody that you see during the nine long months of pregnancy talks about it.”

The traditional approach to an unknown risk is avoidance.

*James F. Clapp*

*Original Research*

# Sleep Position, Fetal Growth Restriction, and Late-Pregnancy Stillbirth

*The Sydney Stillbirth Study*

*Adrienne Gordon, FRACP, PhD, Camille Raynes-Greenow, MPH, PhD, Diana Bond, RN,  
Jonathan Morris, FRANZCOG, PhD, William Rawlinson, FRACP, PhD, and Heather Jeffery, FRACP, PhD*

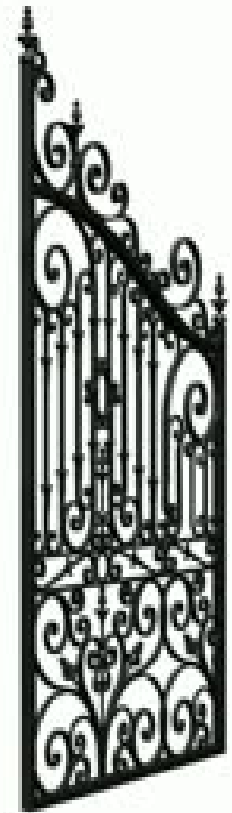
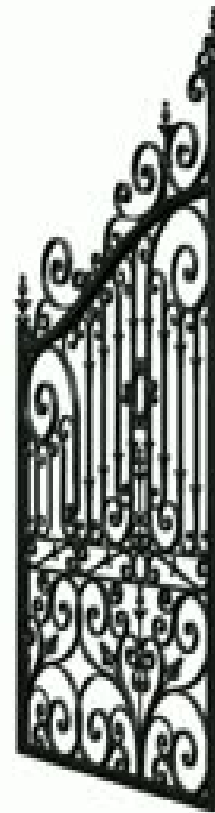
# The Dilemma

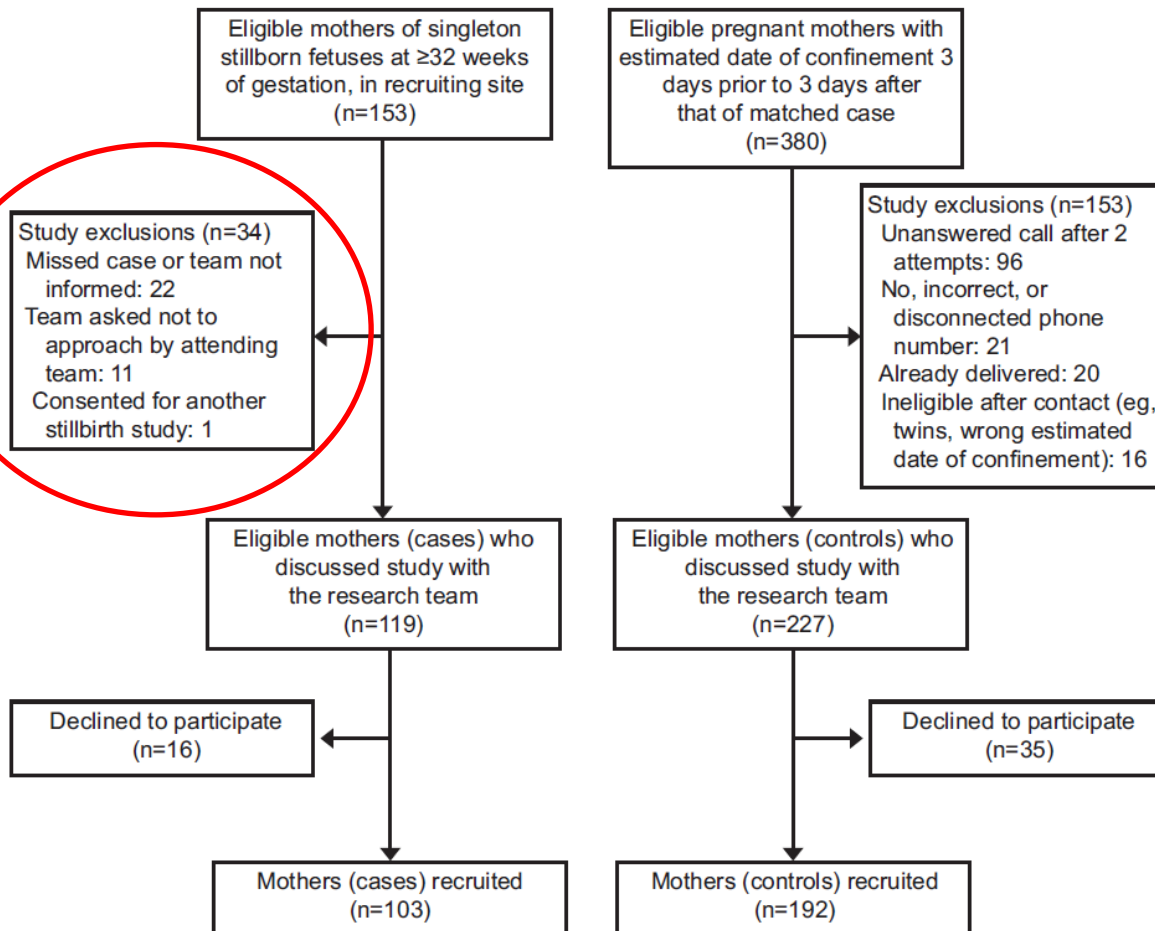
- 'Cold calling' healthy pregnant women to participate in '**sensitive**' research (controls)
- Approaching bereaved women soon after learning their baby had died (cases)



# The Gatekeepers

- Ethics Committees
- Research Governance
- Clinical staff
- Family members





**Fig. 1.** Study flow chart.

Gordon. *Risk Factors for Late-Pregnancy Stillbirth*. *Obstet Gynecol* 2015.

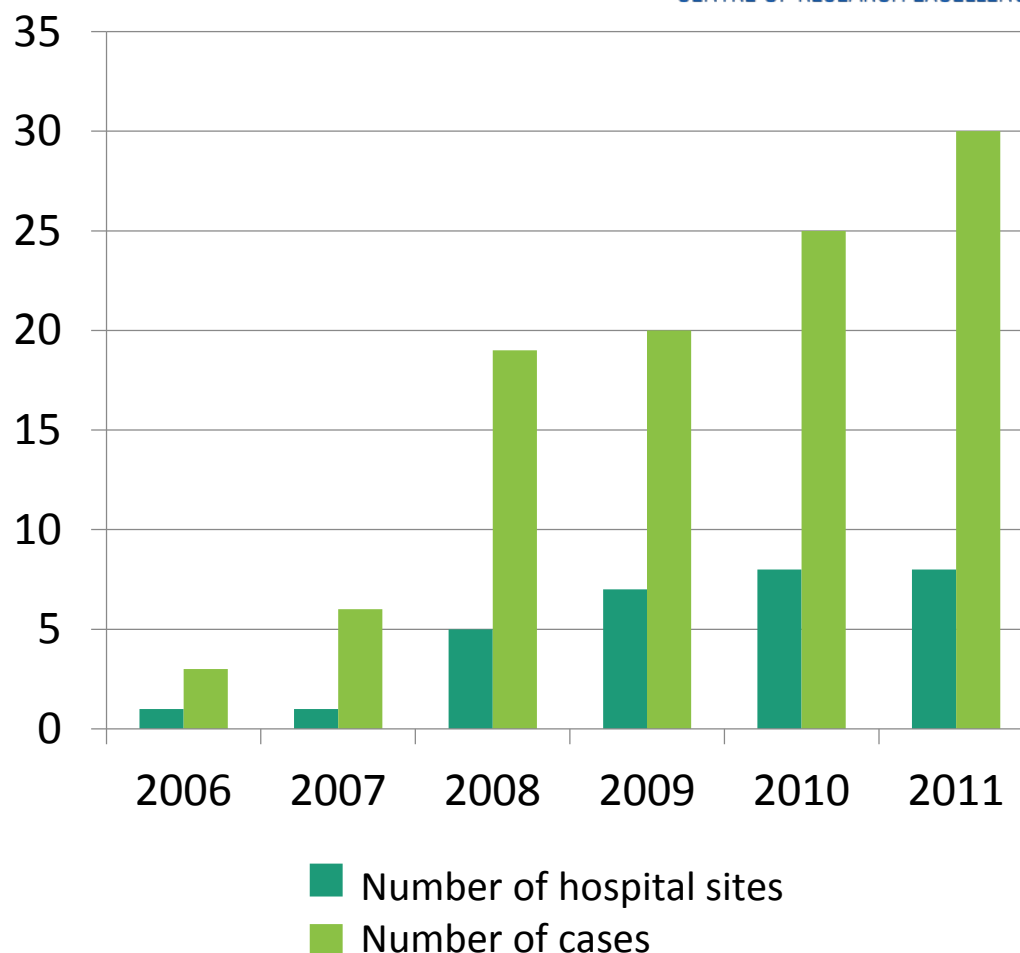
# Recruitment

- **Cases – 103**

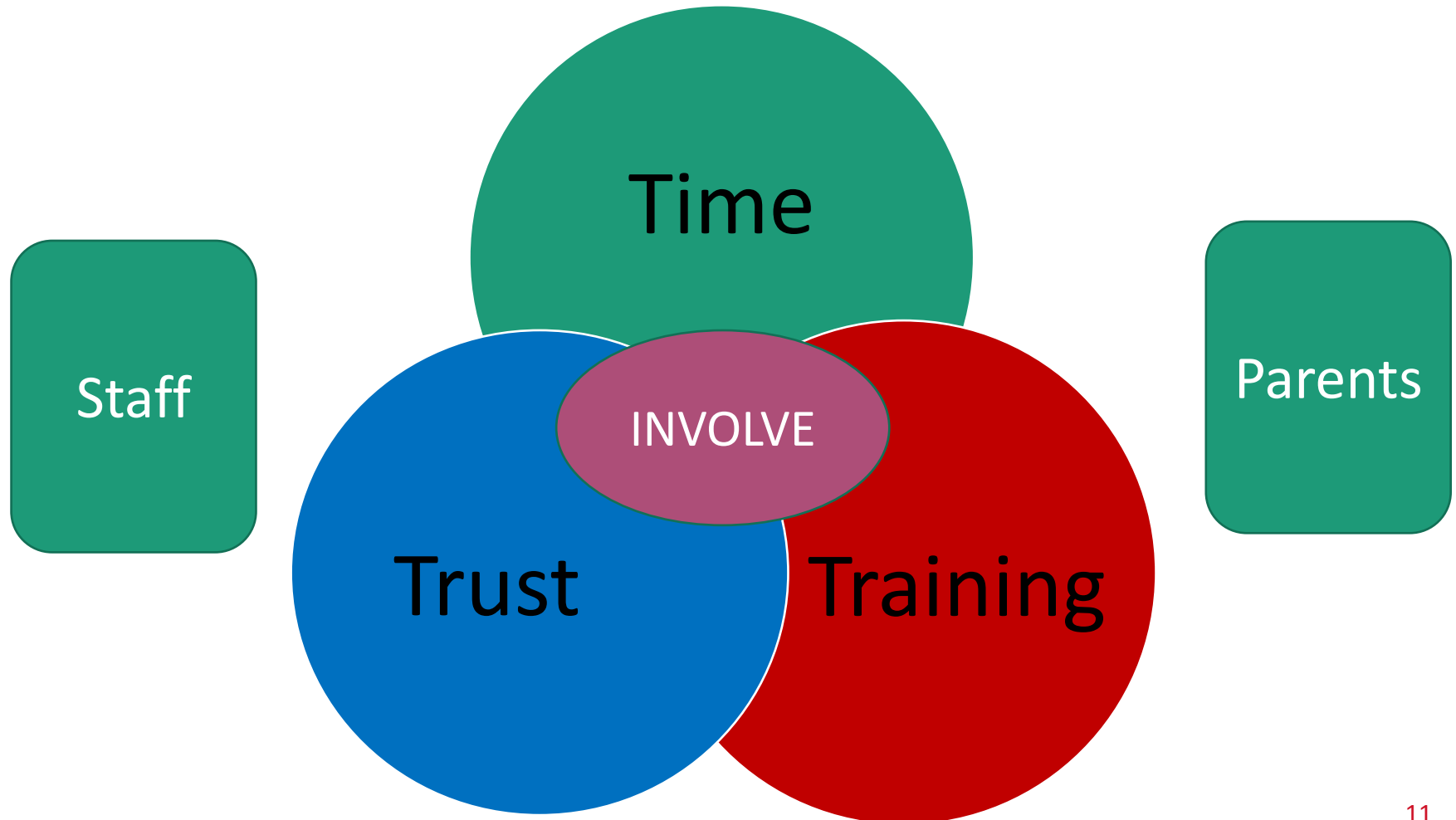
- 67% of eligible
- 87% of those who team allowed to approach

- **Controls – 192**

- 86% of eligible and approached



# Facilitators





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## Midwifery

journal homepage: [www.elsevier.com/midw](http://www.elsevier.com/midw)



## Anxiety and acceptability related to participation in stillbirth research



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# Aim

- The aim of this study was to explore the anxiety levels and acceptability of parents (both cases and controls) participating in a stillbirth study of an etiological nature involving in-depth structured interviews.



# Methods

Sydney Stillbirth Study

2006 – 2011  
Recruitment

Anxiety / Acceptability Study

February 2012  
Questionnaires

	Not at all	Somewhat	Moderately	Very much
a. I feel calm				
b. I am tense				
c. I feel upset				
d. I am relaxed				
e. I feel confident				
f. I am worried				

# Participants

Maternal Characteristics	Responders n=101 (%)	Non-responders n=194 (%)	P value
Maternal age <35	62 (61.4)	132 (68)	n.s.
35 - 39	27 (26.7)	48 (24.7)	
>/= 40	12 (11.9)	14 (7.2)	
Primiparous	53 (52.5)	104 (53.6)	n.s.
Private care	39 (38.6)	42 (21.6)	0.002
Term	88 (87.1)	167 (86.1)	n.s.
Not in paid work	4 (4)	40 (20.6)	0.000
Living with partner	99 (98)	175 (90.2)	0.013
Smoking	10 (9.9)	29 (14.9)	n.s.
Adverse social	5 (5)	21 (10.8)	0.091
Tertiary education	82 (81.2)	121 (62.4)	0.001
Born overseas	39 (39)	94 (48.5)	n.s.

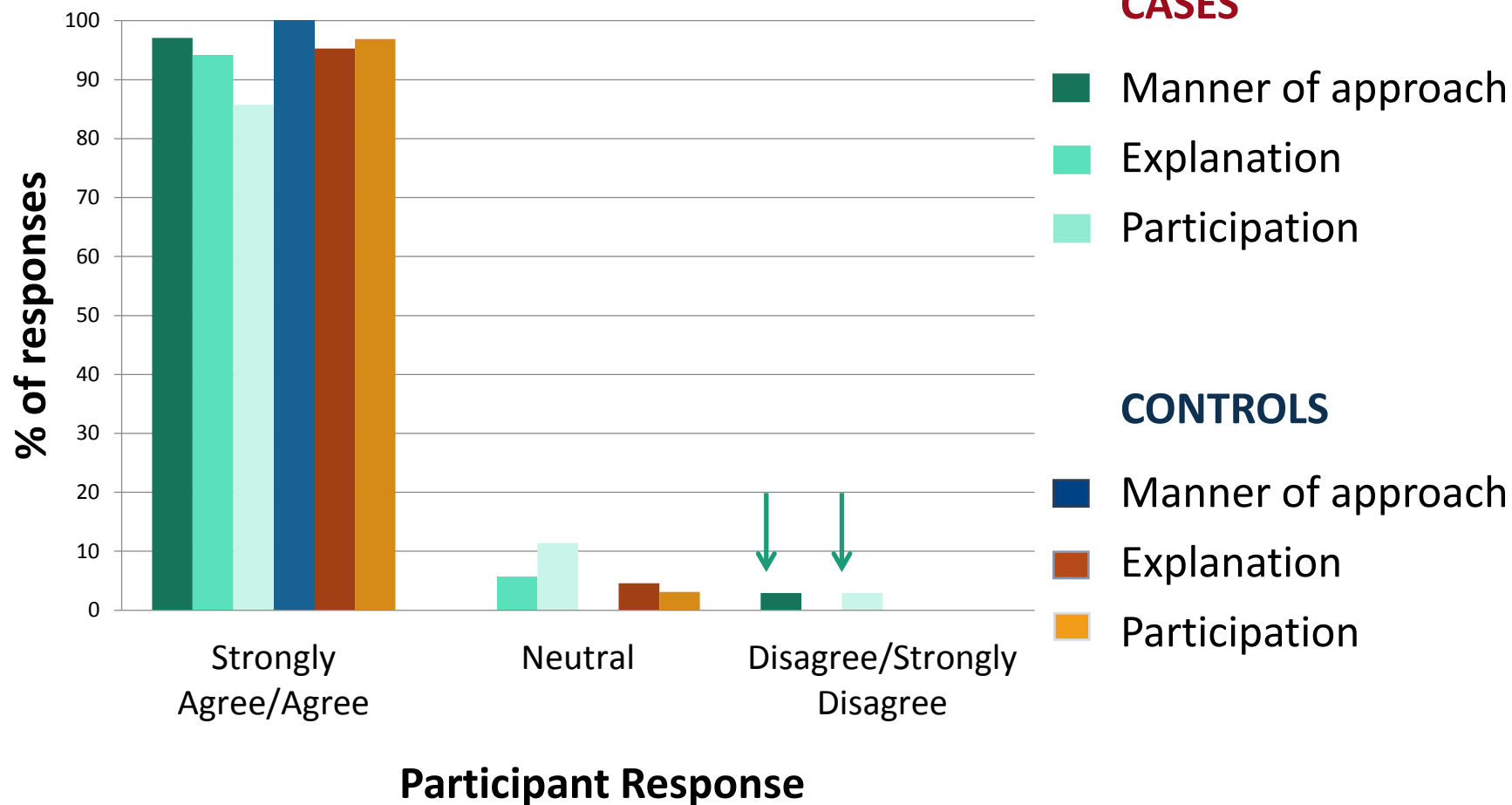
# Results - Anxiety

100

*“Even though I've said I was anxious when asked to participate and during the interview, I was still more than happy to go through with it. The anxiety was simply brought to the fore because of discussing it. I believe it would be present in any expectant mother's mind.”*

# Results - Acceptability

## Satisfaction



# Comments

*“Being part of this study helped*

*“I was glad to help. I also have to say that the interview and phone calls/emails I had with the research officer were very professional but friendly and 'warm'. I hope you can learn a lot from this study. Thanks.”*

# Key themes

## Attributing meaning

‘It helped us feel that (our baby's) life meant something, that he made a contribution, no matter how small.’

‘So that there is a chance something positive might come out of the death of our daughter-even if it is just how you might be treated at the time.’

## Strengths:

- Validated anxiety scale
- Pilot tested questionnaire
- 1<sup>st</sup> time study using controls

## Limitations:

- › Small sample size
- › Low response rate
  - Similar for both cases and controls
  - Similar to other studies in literature

# Conclusions



- High levels of satisfaction amongst both cases and controls.
- No significant increase in anxiety in either cases or controls.
- Contrary to 'gatekeeper' concerns, women WANT to be involved in stillbirth research
- Acceptability of study reflected in staff attitude
- An empathic and professional approach is important.
- Further research would be of benefit – especially staff response

*“I was dreading this interview, and as you know, kept postponing the appointments, but I am surprised at how good I feel. It is such a relief to talk to someone about this.”*

# Acknowledgements



- The amazing families who were part of the Sydney Stillbirth Study
- **Stillbirth Study Research team** – Prof Heather Jeffery, Dr Camille Raynes-Greenow, Prof Jonathan Morris, **Diana Bond**, Rachel Jones, Angela Carberry
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  - Canterbury
  - Nepean
  - Royal North Shore
  - Royal Womens
  - Mater
  - Liverpool
  - Westmead
  - North Shore Private



Stillbirth  
Foundation  
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Research and education to prevent stillbirth

# Thank-you

