

Confident Conversations; empowering parents to make choices to prevent their baby dying from Sudden Unexpected Death in Infancy

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24TH ANNUAL
INTERNATIONAL MEETING

@bfmedicine #bfmed2019



No conflicts

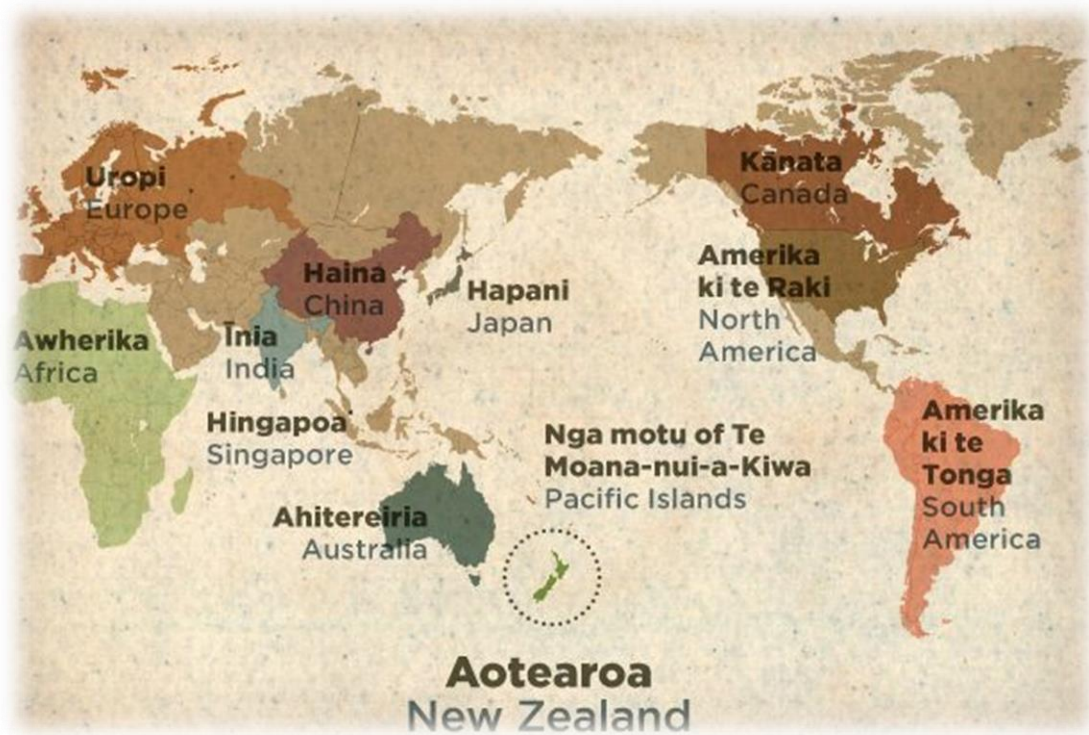
2015-19 Cure Kids funded research

Sponsors: Perpetual Guardian & Procure Foundation



**MEDICAL AND
HEALTH SCIENCES**



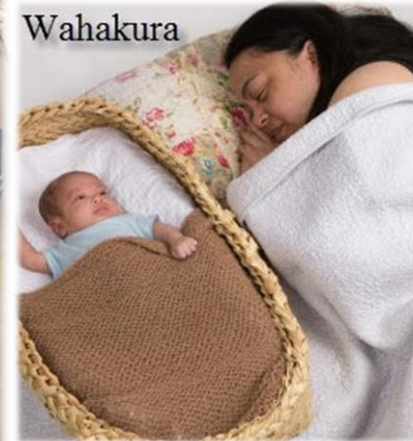


Safe Sleep Spaces improve breastfeeding rates

Provision of a wahakura or Pepi-pod as part of a safe sleep education programme significantly improves breastfeeding rates.

- Pepi-pod RCT infant age 4-months (any breastfeeding): 54% intervention group vs 32% control group $P = 0.03$ ¹
- Wahakura vs Bassinet RCT at age 6-months (full breastfeeding) 22.5% vs 10.7%, $P = 0.04$ ²

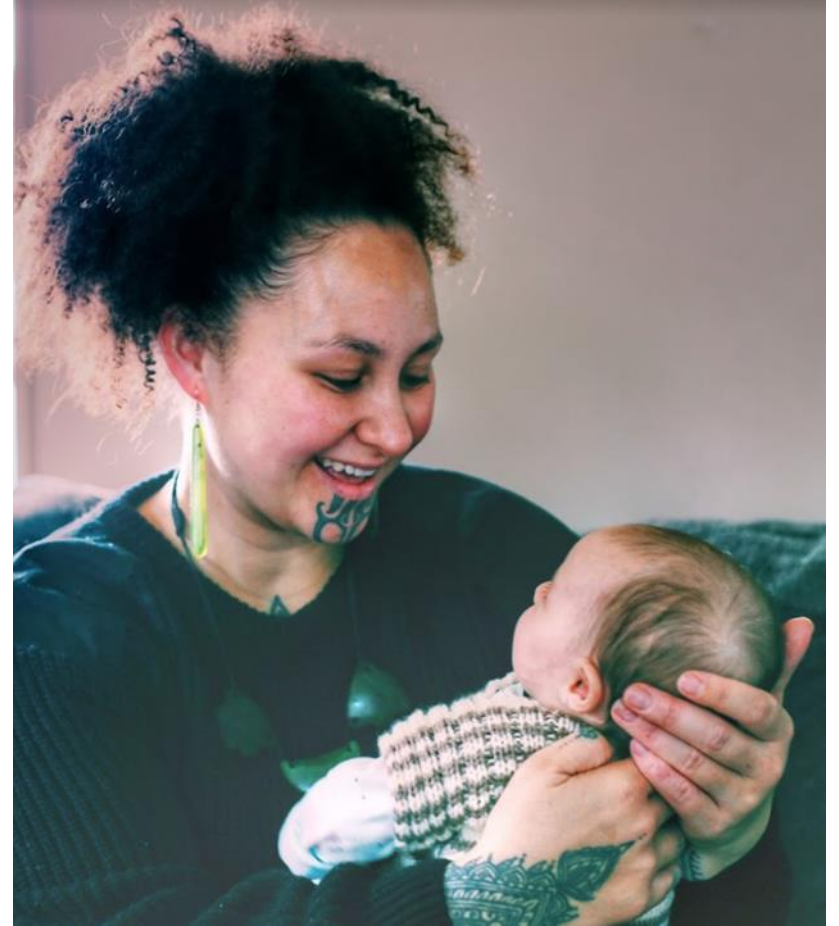
1. McIntosh C, Trenholme A, Stewart J, Vogel A. Evaluation of a Sudden Unexpected Death in Infancy intervention programme aimed at improving parental awareness of risk factors and protective infant care practices. *J Paediatr Child Health*. 2017 Nov 10. doi: 10.1111/jpc.13772.
2. Baddock SA, Tipene-Leach D, Williams SM et al. Wahakura versus bassinet for safe infant sleep: A randomized trial. *Pediatrics* 2017;139: e20160162.





Overview

- What is SUDI
- SUDI messaging
- Calculating the risk
- Confident conversations
- Objective and targeted



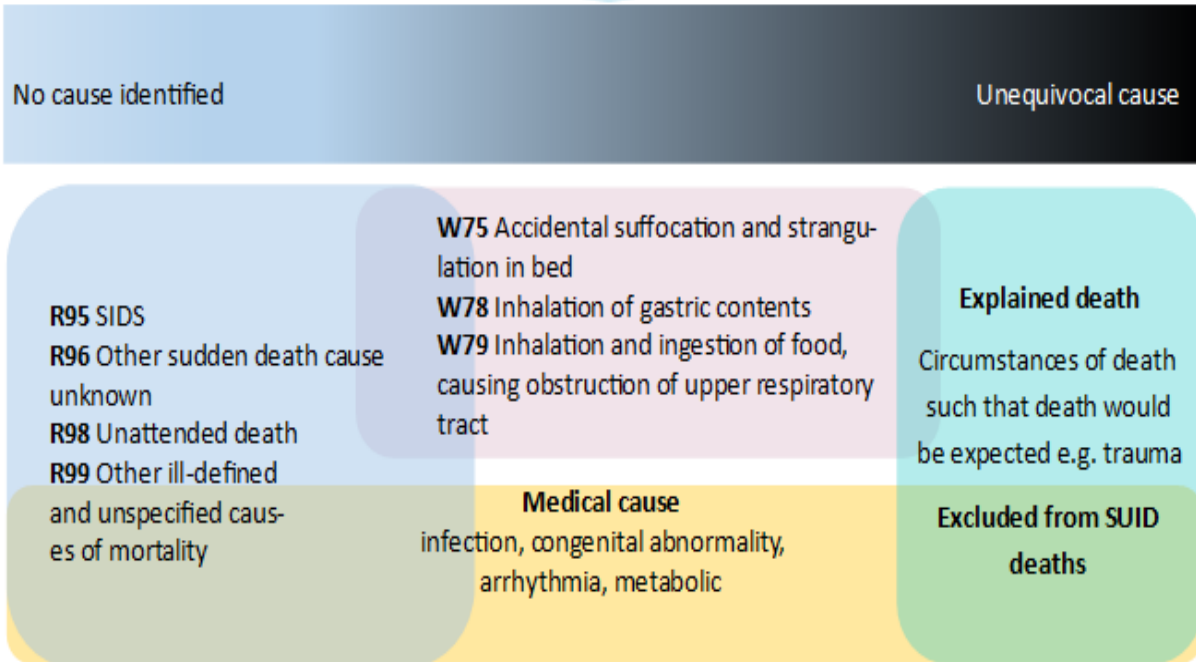
How do we support Kate and her partner to prevent SUDI?

Kate is 22 years old. She smokes, no alcohol or drugs. Her partner does not smoke. Her baby is a boy, BW 2850g.

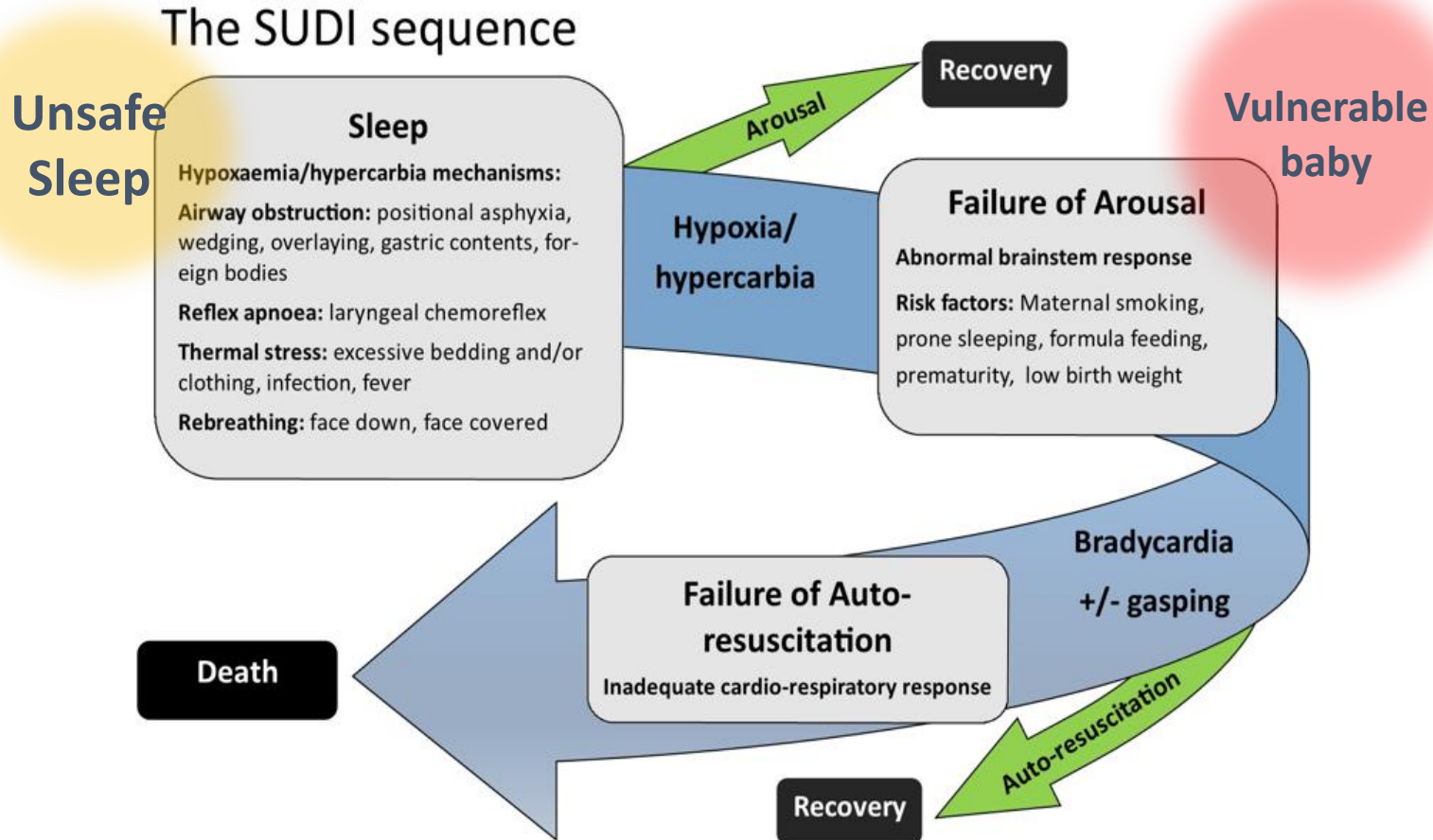
She's sleeping baby Sam on his side she's bed-sharing. She's not sure she wants to continue breastfeeding.

Sudden Unexpected Death in Infancy

Clinical history, death scene investigation, autopsy



SUDI - a lack of response to a breathing problem in sleep



Colonisation
Marginalisation
Poverty

Young baby,
LBW/SGA
Prone sleep,
Smoking,
Alcohol,
Drugs,
Prematurity,
Young mother,
Formula
feeding

Vulnerable
baby

and

Unsafe
sleep

SUDI



Prone & side
sleeping,
Alcohol,
Drugs,
Bed-sharing,
Overheating,
Pillows,
Face covering



**Young baby,
LBW/SGA
Prone sleep,
Smoking,
Alcohol,
Drugs,
Prematurity,
Young mother,
Formula feeding**

**Vulnerable
baby**

and

**Safe
sleep**

Alive



**Own Baby bed
On back
Face clear**



...the advice she received from health professionals was confusing and contradictory, she says.

...Coroner Wallace Bain's condemnation was not directed toward the mothers of dead babies, it was a "criticism of our system and the information we impart".

NZ Herald 9 July 2016



Effective SUDI Messaging and Interventions

1. Multi-pronged, consistent messaging across multiple levels.
2. Safe sleep interventions should be crafted specifically for higher risk groups.

Salm Ward TC, Balfour GM. Infant safe sleep interventions, 1990-2015: A Review. *J Community Health*. 2016;41(1):180-196

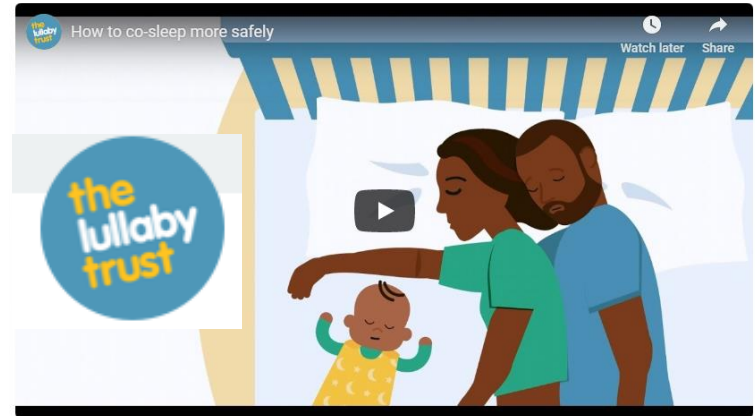
Messaging



American SIDS Institute

The challenges

- Too many messages!
- Who is the target audience?
- What is the priority message?
- SUDI risk is not the only consideration.



Our co-sleeping advice



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In an ideal world...

THE SAFE SLEEP SEVEN BEDSHARING SONG

(to the tune of “Row, Row, Row Your Boat”)

No smoke, sober mom
Baby at your breast
Healthy baby on his back
Keep him lightly dressed.
Not too soft a bed
Watch the cords and gaps
Keep the covers off his head
For your nights and naps.

Excerpted from [*Sweet Sleep: Nighttime and Naptime Strategies for the Breastfeeding Family*](#), Chapter 2: The Safe Sleep Seven, by Diane Wiessinger, Diana West, Linda J. Smith, Teresa Pitman, a La Leche League International book, Ballantine Books, 2014.



<https://www.babycentre.co.uk/x7766/how-can-i-make-co-sleeping-safe>

ABM

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The reality in NZ...

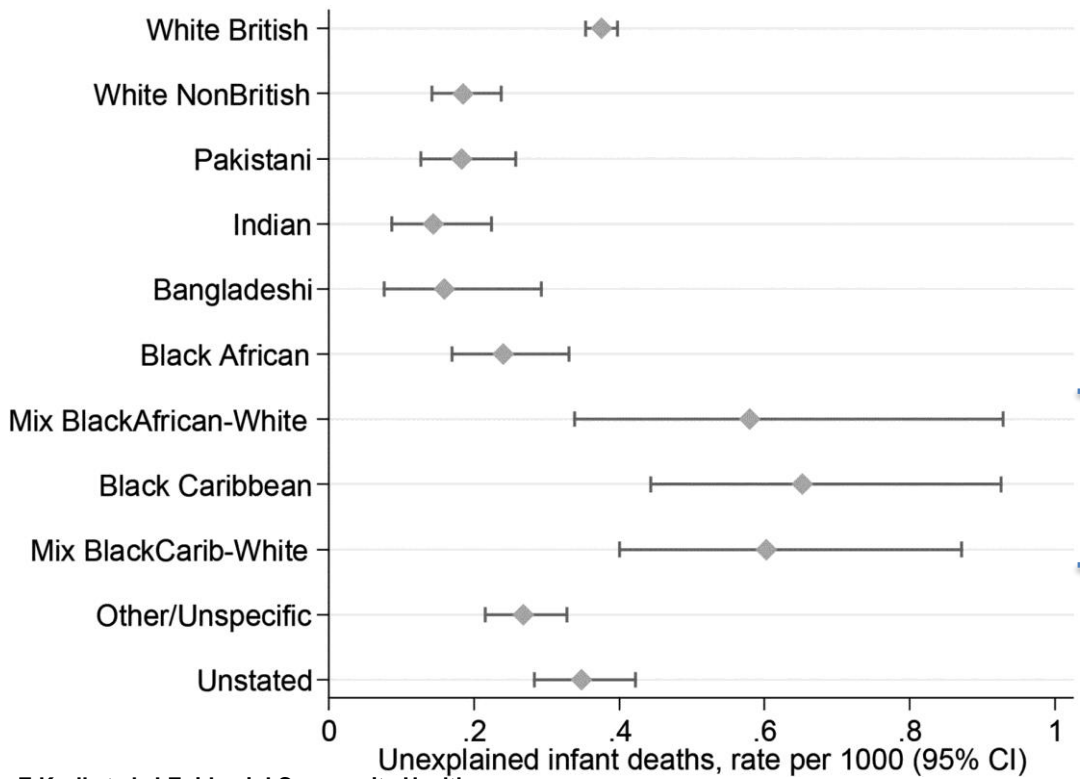


Kartya Walker, Go Petition; Healthy Homes, Healthy Families, May 2016, <https://www.gopetition.com/petitions/healthy-homes-healthy-families.html>



Olivia Carville. Poverty strikes at home, children first victims. Stuff, Feb 15 2013, <http://www.stuff.co.nz/ipad-editors-picks/8306750/Poverty-strikes-at-home-children-first-victims>

Unexplained death in infancy, by ethnic group in England and Wales 2006-2012.



65% births, 73% of SUDI

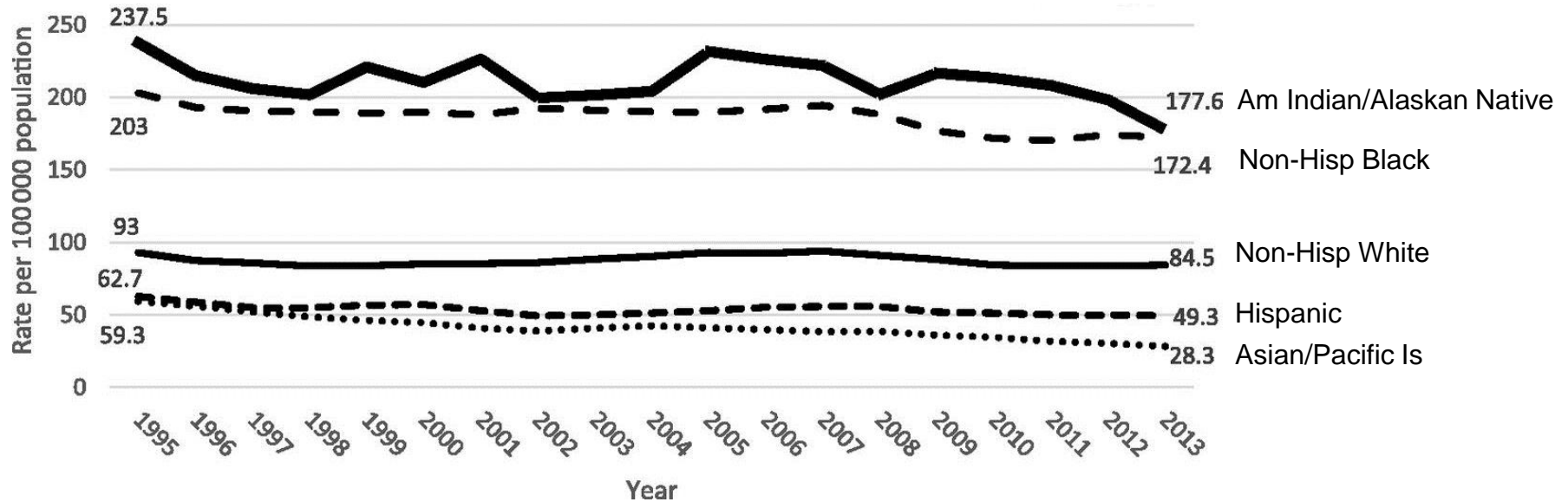
Greatest number of SUDI in the largest birth cohort

3% births, 5% of SUDI

Mary E Kroll et al. J Epidemiol Community Health
2018;72:911-918 ©2018 by BMJ Publishing Group Ltd

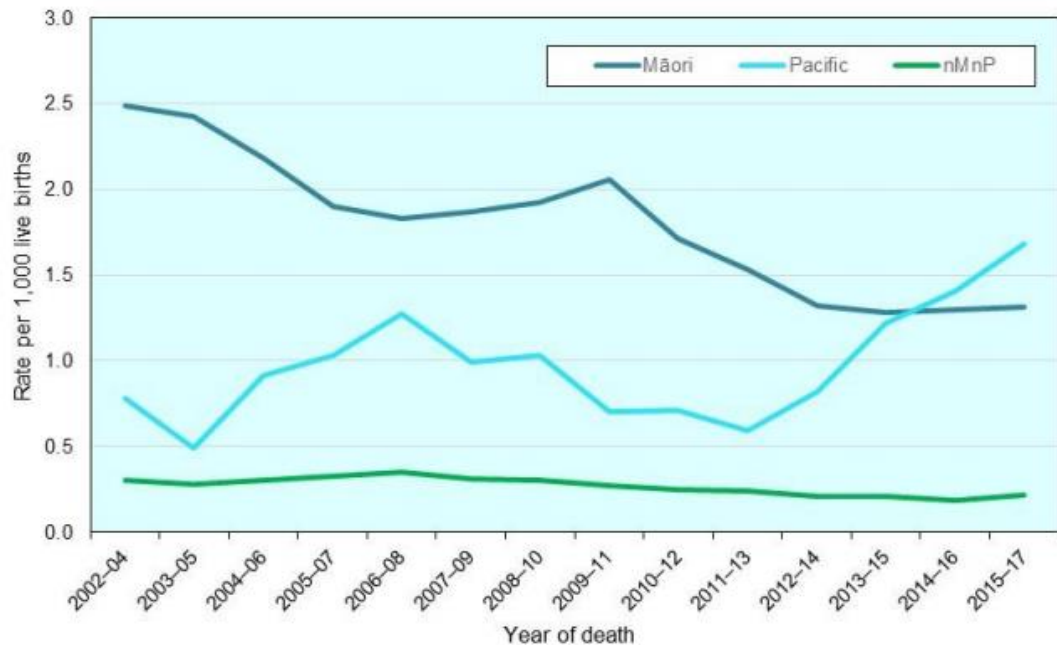


Trends in SUID: rates per 100 000 live births by race/ethnicity: United States, 1995–2013.



Sharyn E. Parks et al. *Pediatrics* 2017;139:e20163844 ©2017 by American Academy of Pediatrics

Figure 4.2: Post-neonatal SUDI mortality (three-year rolling rates per 1,000 live births) by prioritised ethnic category and year of death (rolling three-year periods), Aotearoa/New Zealand 2002–17 (n=764 deaths*)



Ethnicity	Rate per 1000 live births (95% CI)	Deaths 5 years
Māori	1.36 (1.11-1.60)	116
Pacific	1.35 (0.97-1.83)	41
Non-M Non-PI	0.21 (0.15-0.29)	38

* Excludes one case with unknown ethnicity.

nMnP = non-Māori non-Pacific.

Sources: Numerator: Mortality Review Database; Denominator: Ministry of Health Live Birth Registrations 2002–16, NZMRDG 2017.

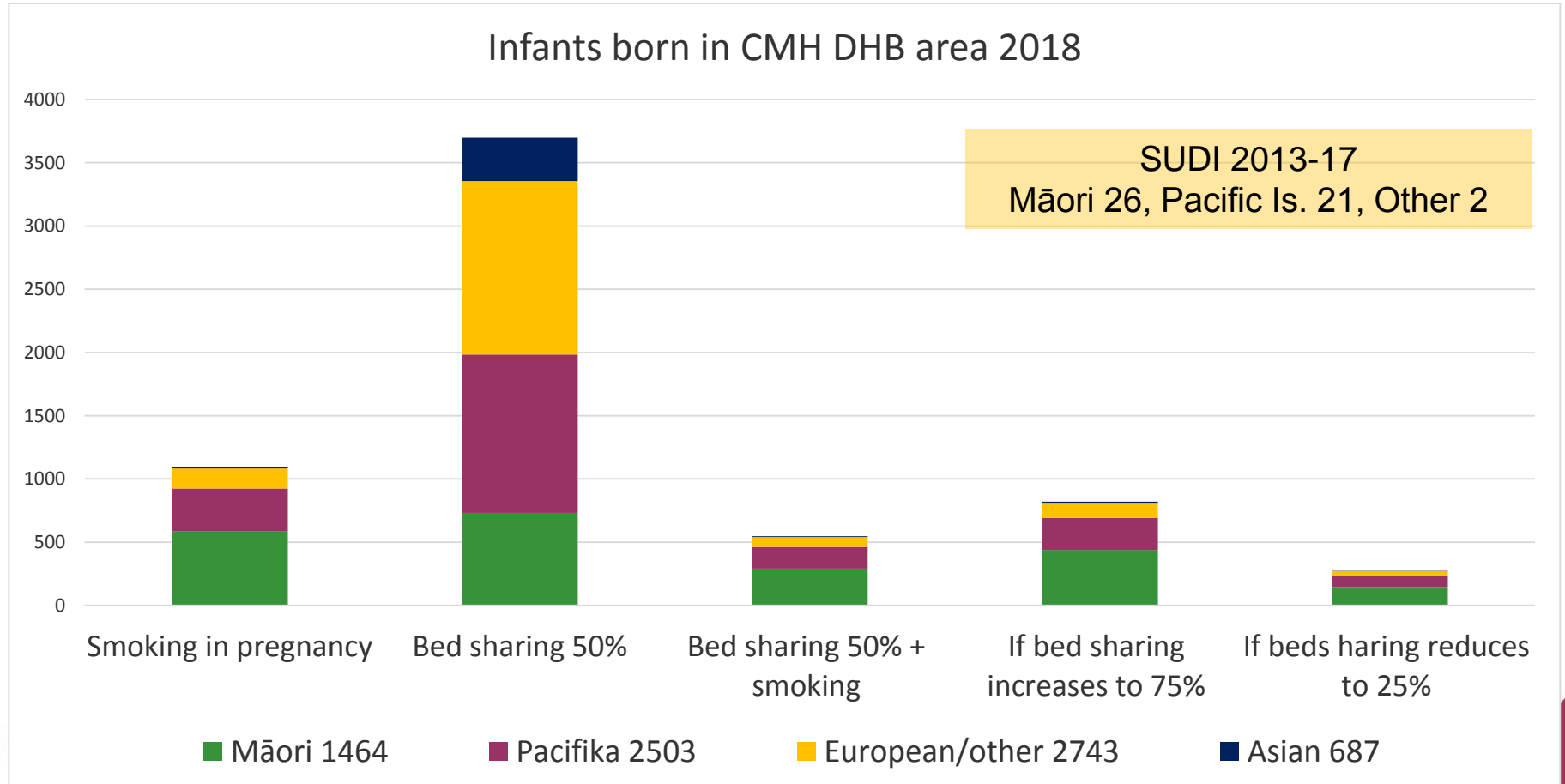
Maternal smoking & bed-sharing significantly increases risk

Table 2: Interaction between maternal smoking in pregnancy and bed sharing on risk of SUDI.

		Cases	Controls	Univariable OR (95%CI)	Multivariable * OR (95%CI)
Smoking	Bed sharing	(missing=10)		p=0.033 (interaction)	p=0.002 (interaction)
No	No	21 (17.1)	138 (53.5)	1.00	1.00
No	Yes	11 (8.9)	29 (11.2)	2.75 (1.17, 6.48)	1.59 (0.52, 4.87)
Yes	No	32 (35.2)	74 (28.7)	2.64 (1.33, 5.26)	1.91 (0.77, 4.72)
Yes	Yes	59 (48.0)	17 (6.6)	31.1 (14.0, 69.3)	32.8 (11.2, 95.8)

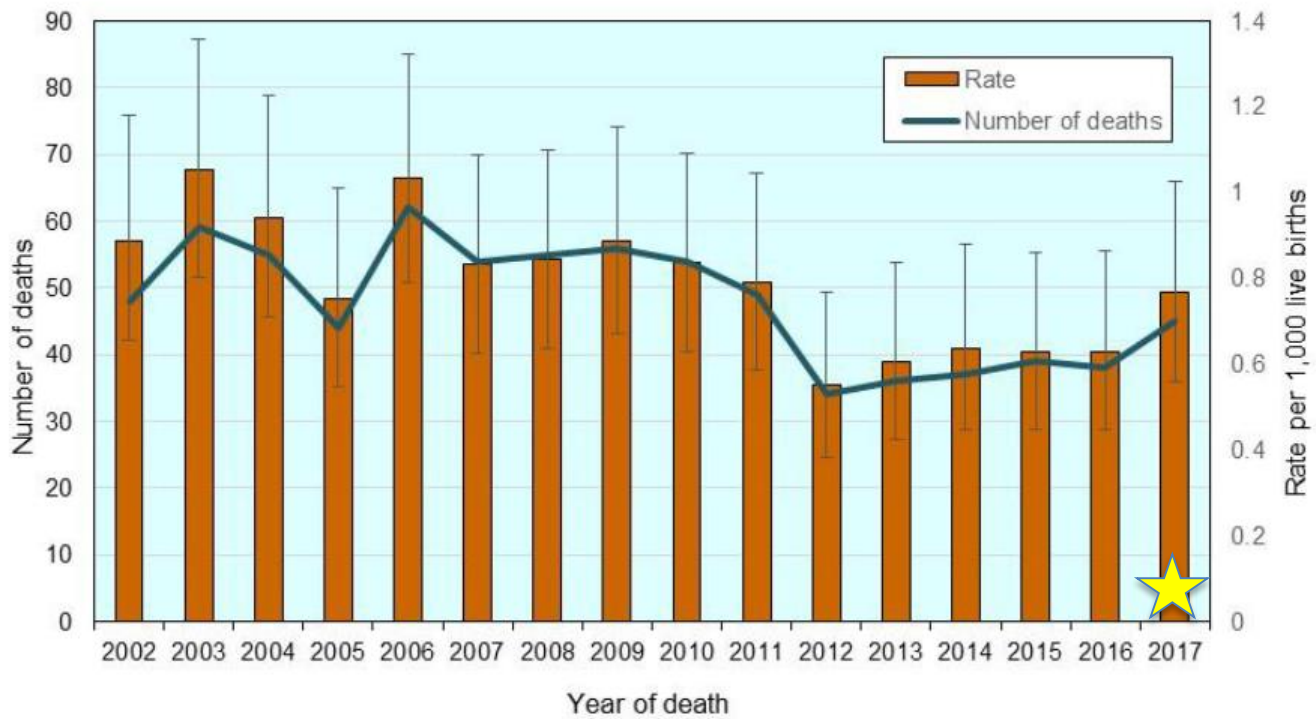
Edwin A Mitchell, John MD Thompson, Jane Zuccollo, et al. **The combination of bed sharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study.** *NZ Med. J.* 2nd June 2017, Volume 130 Number 1456.

There is a trade-off when messaging about bed-sharing



Effective enough?

Figure 4.1: Post-neonatal SUDI mortality (number of deaths and rates per 1,000 live births) by year of death, Aotearoa/New Zealand 2002–17 (n=765 deaths)



Sources: Numerator: Mortality Review Database; Denominator: Ministry of Health Live Birth Registrations 2002–16, NZMRDG 2017.

Safe Sleep for P.E.P.E



Place baby in their own baby bed in the same room as their parent or caregiver

Eliminate smoking in pregnancy and protect baby with a smokefree whaanau, whare and waka

Position baby flat on their back to sleep - face clear of bedding

Encourage and support exclusive breastfeeding and gentle handling of baby



Call Plunket Line on 0800 933 922 for parenting and health advice

NO one set of SUDI prevention messages works for everyone.

Risk and Protective Factors

Combined data from 5 case control studies:
ECAS , Scottish, New Zealand, Irish, GeSID

Risk factors multiply and some interact

Carpenter R, McGarvey C, Mitchell EA, et al. Bed sharing when parents do not smoke: Is there a risk of SIDS? An individual level analysis of five major case-control studies. *BMJ Open*. 2013;3(5):10.1136/bmjopen-2012-002299.

Hauck FR, Omojokun OO, Siadaty MS. Do pacifiers reduce the risk of sudden infant death syndrome? A meta-analysis. *Pediatrics*. 2005;116(5):e716-23.

Risk factors		Multivariate Odds Ratio	95%Confidence Intervals
Maternal and paternal smoking	Mother	1.5	1.2-2.1
	Father	1.1	0.8-1.4
	Both	2.9	2.3-3.6
Bed-sharing* < 3 months' age		2.7	1.4-5.3
Not breastfeeding		1.5	1.2-1.8
Sleep position	Side	1.5	1.2-2.1
	Prone	10.5	7.5-14.6
Maternal drug and or alcohol use	Alcohol (> 2 units in last 24 hours)	4.8	2.6-8.9
	Illegal drugs since baby born	11.5	2.2-59.5
Male gender	Matched studies	0.8	0.6-1.1
	Unmatched studies	1.6	1.3-1.9
Ethnicity 'non-white'		1.5	1.1-1.9
Low birth weight	2500-3499g	1.7	1.4-2.0
	2000-2499	4.2	2.9-6.0
	< 2000g	9.6	6.2-14.7
Younger maternal age	26-30 years	1.9	1.5-2.3
	21-25	3.0	2.4-3.8
	19-20	7.7	5.2-11.4
	18 and under	9.1	5.9-14.1
Higher birth order	2	2.3	1.9-2.9
	5 or more	7.7	5.3-11.3
Pacifier use		0.4	0.3-0.5
Mothers marital status	Single	1.9	1.5-2.4
Not sleeping in same room as parent		2.4	2.0-2.9

An opportunity for individualised SUDI Risk Assessment

Voda NZ 4:35 PM 87%

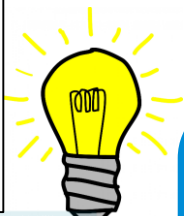
cure kids
SUDI Risk Calculator

Child Factors

Gender Male Female

Date of birth

Birth Gva



SUDI Risk App.
Mitchell 2014

Carpenter et. al.
SUDI case control
study meta-
analysis
2013

Safe Sleep Calculator
Webform
Primary Care pilot
McIntosh
2016-17

Safe Sleep Calculator – A
strategic approach to SUDI
prevention Care 2018-19

Calculate Risk This is real data and can be submitted to the research database

HealthPathways (Auckland) HealthPathways (3D)

Key messages:

- Place baby in their own baby bed in the same room as their parent or caregiver.
- Eliminate smoking in pregnancy, and protect baby with a smokefree whanau(family), whare (home) and waka (car).
- Position baby flat on their back to sleep - face clear of bedding.
- Encourage and support exclusive breast feeding and gentle handling of baby.

Sleep safety scale for Sudden Unexpected Death in Infancy risk:

1 in 40,000	Very Low Risk
1 in 20,000	
1 in 10,000	
1 in 5,000	
1 in 2,500	
1 in 1,000	
1 in 500	
1 in 100	
1 in 50 babies	Very High Risk

Currently your baby's risk level is: **1 in 243 babies**

You can make your baby safer for every sleep by:

	Making only this change:	Adding changes together:
Avoiding bed sharing	1 in 2973	1 in 2973
Mother stopping smoking	1 in 1339	1 in 4163
Avoiding drinking alcohol	1 in 344	1 in 949

(Must be real data and implies parent has given informed consent. No identifiable information will be made available to researchers.)

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MedTech-32 Procon Limited

File Edit Patient Module Report Tools Utilities Setup ManageMyHealth ConnectedCare CBIT CAT Window Help Support Chat

LEECH Baby (O'LEECH.9) Y 3 - R ABC1235
1/35 Sonia Avenue, Remuera 09 Oct 2016 11 mths Female Maori - NZ 130.50

New Safe Sleep Calculator (Procon Limited)

Main Safe Sleep Calculator More Audit

Safe Sleep Calculator

Birth weight: gms
 lbs oz

Is a twin: No Yes

Baby's ethnicity: NZ/European NZ Maori Pacific
 Asian Other Unknown

Mother's age:

Relationship status: Living with partner Single

Number of previous live births:

Modifiable risk factors:

Feeding method: Breast Formula Mixed

Where baby sleeps: Parents bedroom Own bedroom

Sleeping position: On back On side On front

Mother smokes: No Yes

Father smokes: No Yes

Number of days per week mother drinks 2+ units of alcohol:

Mother uses recreational drugs: No Yes

Research request:

The researchers would like to contact parents or caregivers to complete a short questionnaire.

Happy to be contacted for research? No Yes

This is real data and can be submitted to the research database

© Procon Limited 2015 Version 1.2.2 November 2016 MSIE version 7

Print OK Cancel Help

KENSURFACEPRO SFE Last Login: 05 Oct 2017 09:59 AM

The Safe Sleep Calculator

1. Maternal age
2. Parity
3. Ethnicity of infant
4. Gender
5. Infant age
6. Birthweight
7. Twin/multiple
8. Breastfeeding
9. Maternal smoking
10. Father/partner smoking
11. Alcohol use
12. Illicit drug use
13. Sleep room
14. Sleep position
15. Sharing sleep surface (bed-sharing)

Healthcare provider focus groups

“I didn’t have a particular way of talking about it. People asked me about it [SUDI] if they were worried about it ...But it wasn’t actually part of what I did at that check”

“Just showing them if you did this, this would make this difference and as you are going through it step by step and just encouraging them to think about making those changes ... but even making three of the five changes is going to make a difference.”

“... and the higher risk is the more you want to talk about what the possibilities are of trying do something about it.”

“Sometimes we think that we are overwhelmed with the .. problems that they bring, the Pandora box opens up...”

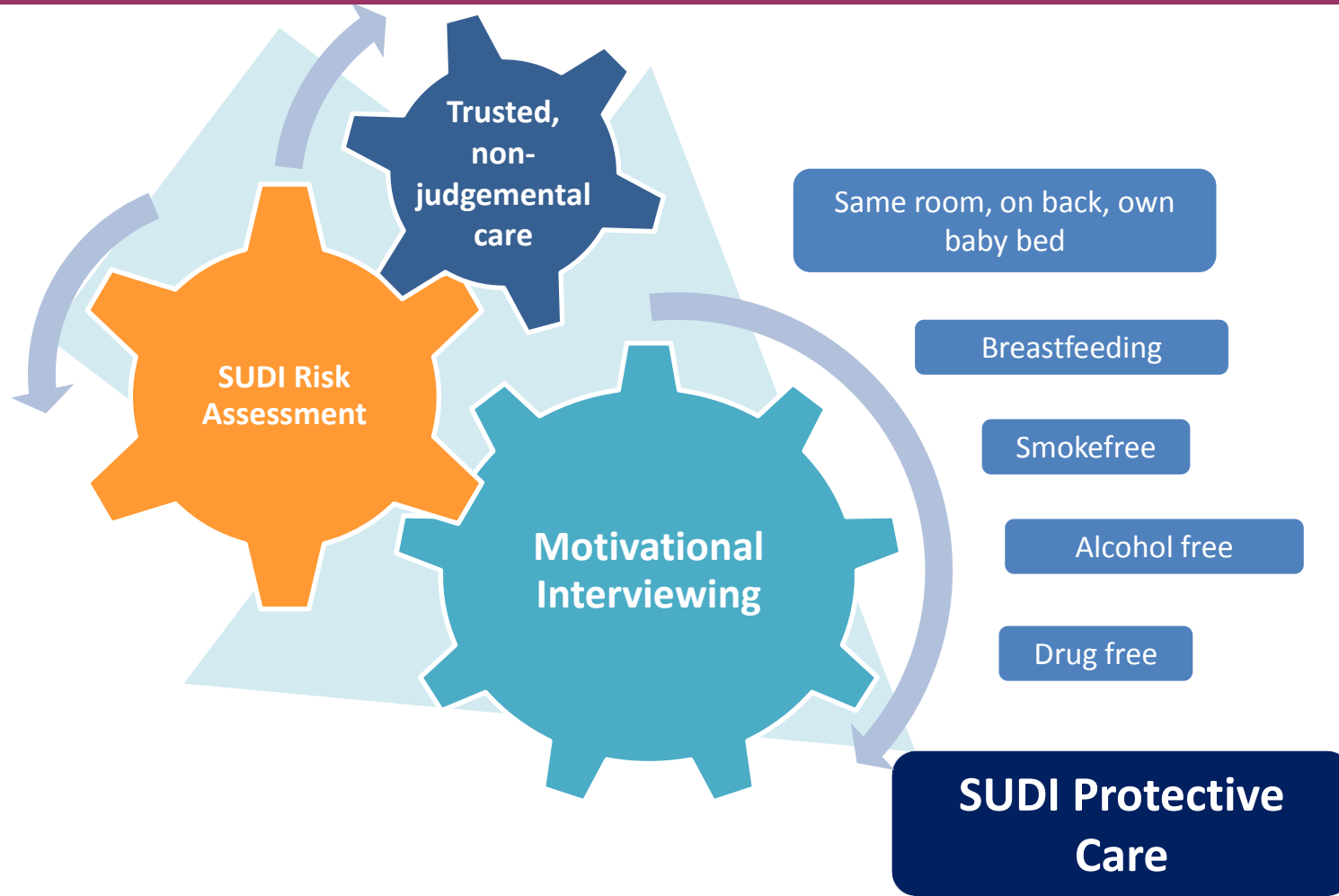
Consumer focus groups

Seven Māori and Pacific focus groups facilitated by Māori and Pacific health researchers

- Wanted to know if their baby was at high risk
- Feared being judged in the process
- Wrap around support for positive change that includes the family



Training for behaviour change conversations



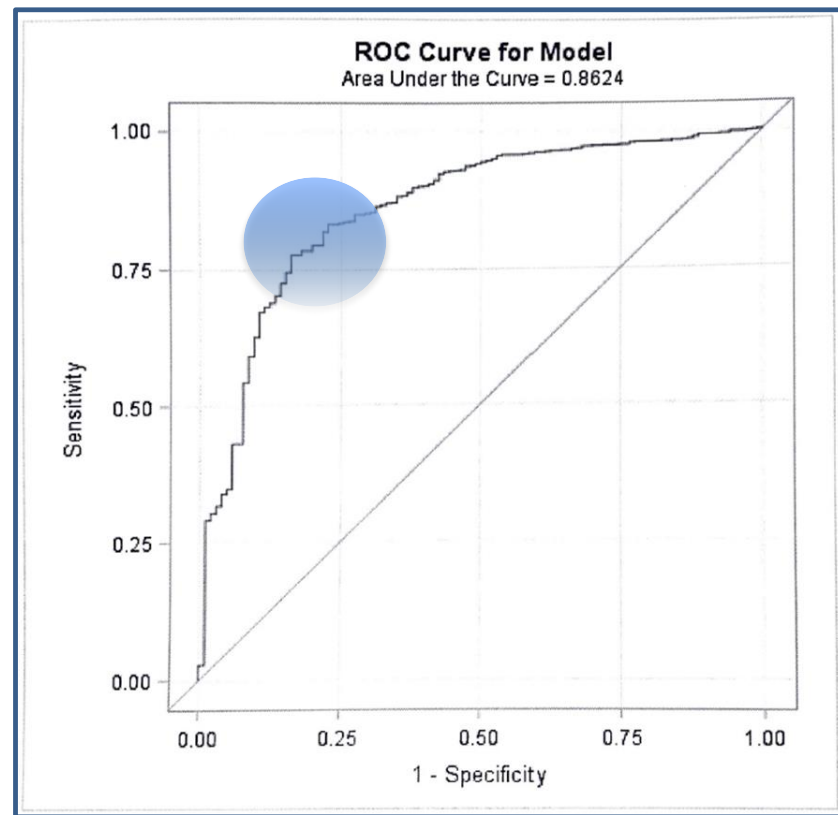
Safe Sleep Calculator Algorithm validation

	NZ SUDI Nationwide Case Control study 2012-15		Safe Sleep Calculator Data 2016-18	NZ population data 2015
	SUDI Cases	Controls		
Mean SSC score per 1000	8.4	0.6	0.1	
Mean maternal age (years)	25.3	28.7	29.4	30
Mean Birth weight (g)	3158	3466	3463	3410
Side/front sleeping (%)	34.1	16.7	6.6	
Breastfeeding (%)	89.8	96.1	79.4	80
Bed sharing (%)	57.5	17.8	9.8	
Maternal smoking (%)	74.2	35.3	17.3	14.2

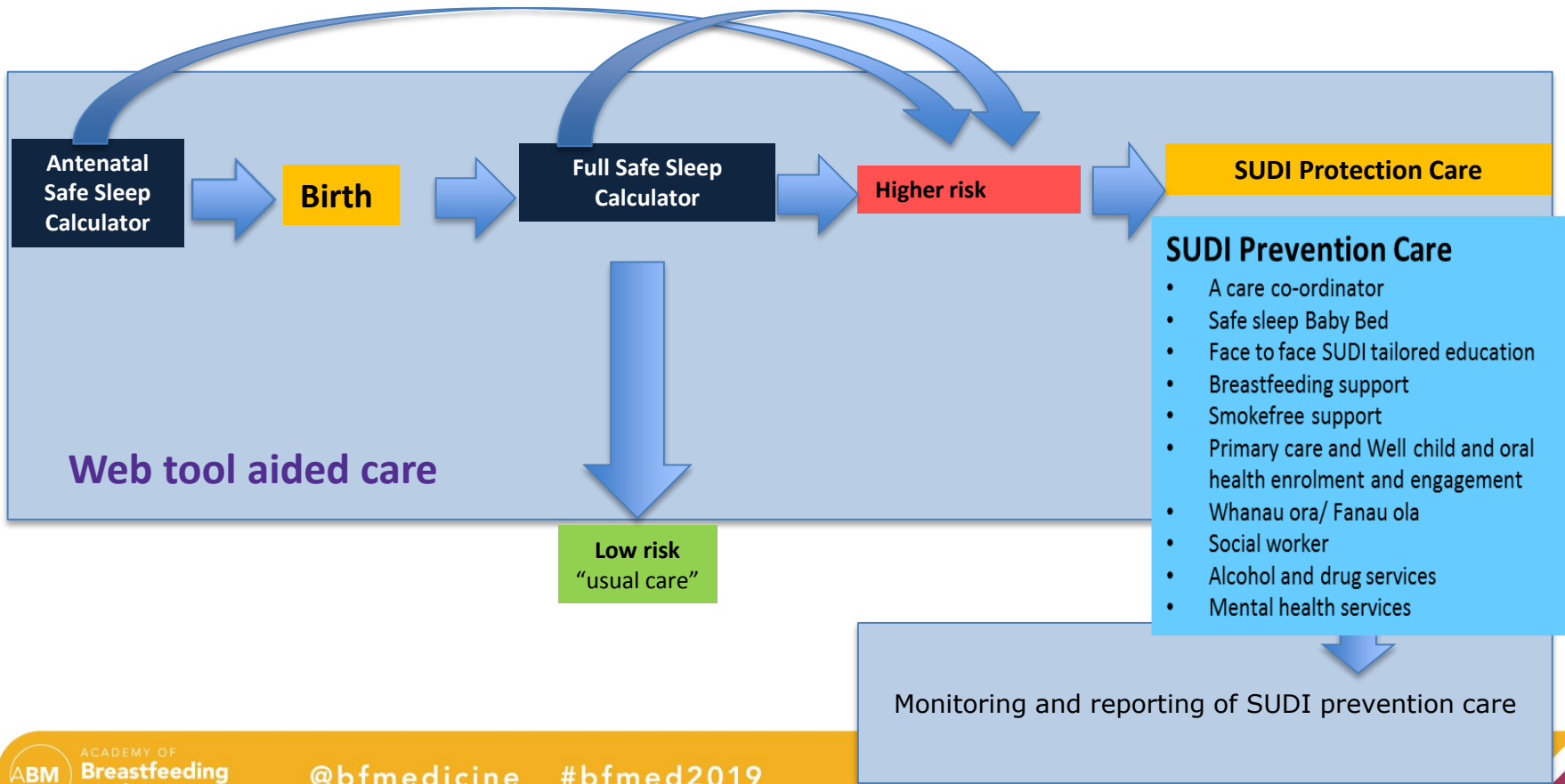
Mitchell E, Thompson J, Zuccollo J *et al.* The Combination of bedsharing and maternal smoking leads to a greatly increased risk of sudden unexpected death in infancy: the New Zealand SUDI Nationwide Case Control Study

80% of SUDI in 21% of higher risk population (higher risk = absolute risk $\geq 0.3/1000$)

AOC 0.86



Creating the SUDI protection care ecosystem



Systematic SUDI prevention model of care

Aims:

- Ensure all families who have a baby at higher risk know that their baby is at increased risk and are therefore empowered to act to reduce risk.
- Targeted SUDI prevention support enables families to reduce modifiable SUDI risk.

Co-design of SUDI Protection Care

Maternity care

- Data
- Review maternity care

Parents said:

- 'Who' and 'how' important
- Non-judgemental
- Wanted to know risk
- Support for positive change
- Cultural considerations

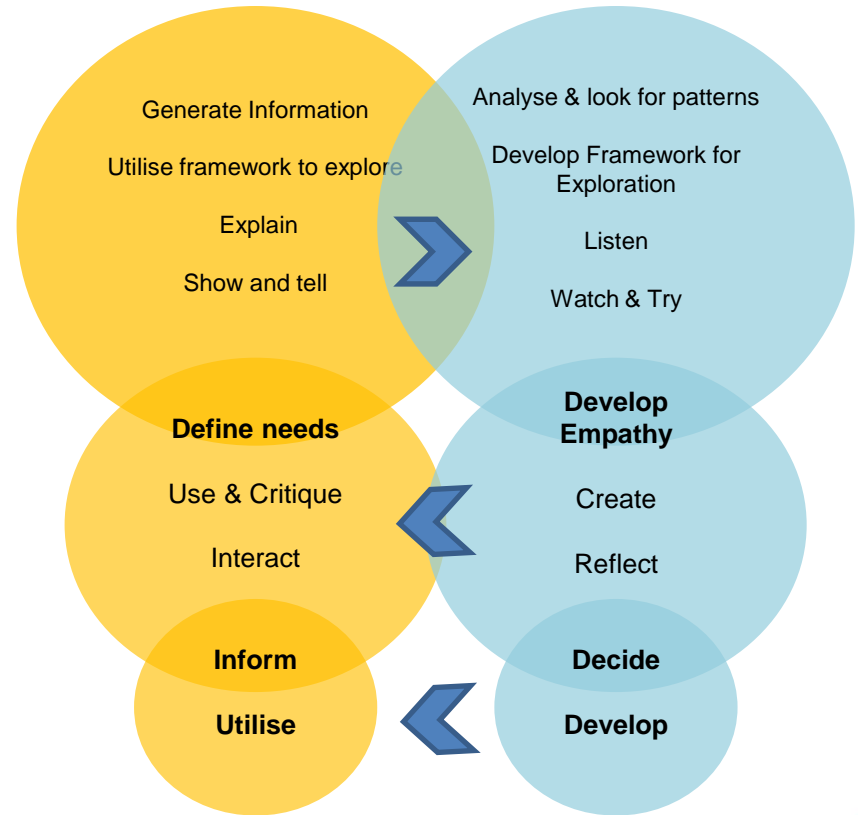
- Training

Midwifery, Neonates DHB said:

- Equity through focussed care
- Scale – big enough to be effective
- Cons

Community providers said:

- Suffic
- Goo
- Work
- Navigator role
- Communication
- Collaborative
- Addressing need
- Culturally competent



Creating the SUDI protection care ecosystem

Develop a SUDI Protection model of care

- Understanding the services
- Virtual integration of providers
- Thinking about workflow
- Minding the 'gaps'
- Distributing baby beds
- Building the software
- Implementation planning
- Monitoring and evaluation

Safe use of digital technology

- Cloud Risk Assessment
- Privacy Impact assessment



Close Send to DHB

Mother/Babies SUDI Protection Care - Mother SUDI Protection Care - Baby 2016

Mother: 33

NHI: ABC1235

Last Name: Mother

First Name: 2016

Ethnicities: Tongan [Edit Ethnicities](#)

Date of Birth: 01/04/2001 19 years old

EDD: 01/07/2019 [Calculate from LMP](#)

Oranga Tamariki involved:

GP: Bader Drive Health Care Mangere [Assign](#)

Midwife: Pauline Malone Non-DHB Midwives [Assign](#)

Well Child Provider: South Seas Healthcare - Otara [Assign](#)

Consent: Mother has provided informed consent to proceed with the SUDI risk assessment

[Save](#)

Babies:

NHI	Name	DOB	Age (weeks)
ABC1235	Baby, 2016	04/06/2019	18

[Update](#)

[Add Baby \(when born\)](#)

1. Midwife login to webform
2. Registers mother (& baby if born)
3. Safety-net for late presenters, prems
4. Midwife prompted to complete full SUDI risk after baby is born.

Postnatal SUDI Assessment

Safe Sleep Calculator

Close

HealthPathways (Auckland)

Baby

Birth Weight

 grams
 lbs oz

Twin/triplet

- No
 Yes
 Don't know

How many babies have you given birth to before this baby? (born alive)

Parents/Caregivers

Who are the people you live with who help to care for your baby? (tick all that apply)

- | | | |
|---|--|--|
| <input type="checkbox"/> Mother (of baby) | <input type="checkbox"/> Father (of baby) | <input type="checkbox"/> Grandparent/s |
| <input type="checkbox"/> Baby's brother/s or sister/s | <input type="checkbox"/> Auntie/uncle/cousin/s | <input type="checkbox"/> Friend/s |
| <input type="checkbox"/> Other caregiver | <input type="checkbox"/> Partner of Father | <input type="checkbox"/> Partner of Mother |

In what ways are you feeding your baby? (tick all that apply)

- Breastfeeding/breast milk Formula

Do you (baby's mother) currently smoke? ⓘ

- No Yes

Do you (baby's mother) currently use an e-cigarette/vape?

- No Yes

Does your baby's father (or partner of mother) smoke?

- No Yes Unsure

Does anyone else who usually lives with you smoke?

- No Yes Unsure

Thinking back over the last month, how often do you have a drink containing alcohol?

- Never Monthly or less 2-4 times a month
 2-3 times a week 4 or more times a month

Have you used drugs in the past month or do you think you will now that baby is born?

1. Speech bubbles – provide suggested conversation and information
2. Questions adapted from qualitative feedback

SUDI Protection Plan for 2016 Baby

SUDI is sudden unexpected death in infancy, also known as SIDS or cot-death

Baby's risk of SUDI is High.

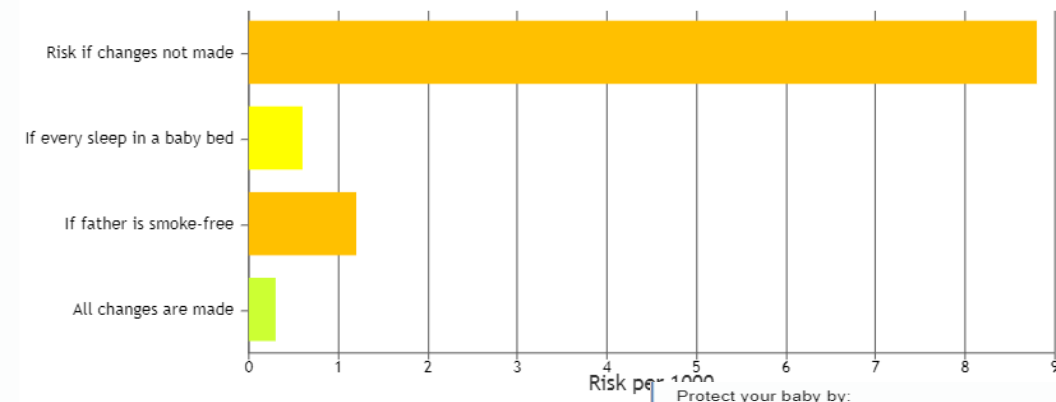
You and your family can make changes that can reduce your baby's risk to Medium-Low.

You and your family are already protecting baby by:

- ✔ Room sharing means you are nearby if baby needs you.

Continuing to be:

- ✔ Alcohol-free. Remember a sober adult needs to look after your baby if you decide to drink. Plan ahead.
- ✔ Drug-free. Remember a drug free adult needs to look after your baby if you decide to use drugs. Plan ahead.



ADDING SUDI PROTECTION BY MAKING CHANGES

Your baby's risk is 1 in 114. Making all the changes will lower your baby's risk to 1 in

Note: The chart and numbers show the reduction in risk as if Smokefree throughout, but not as much as being Smokefree throughout.

Protect your baby by:

- Sleeping baby in their own baby bed for every sleep** will lower risk to 1 in 1720. A baby bed is a bassinet, cot, wahakura or Pepi-pod.
- Baby's father smoke-free** will lower risk to 1 in 832.
- A smoke-free household.** Smoke-free is best for baby during pregnancy and in the home and car
- Breastfeeding is best for baby** (if you can) and it protects against SUDI. Baby's risk would have been lowered. Consider breastfeeding your next baby. Try to breastfeed your baby for at least 6 months and beyond.

Individualised SUDI Protection plan

1. specific for mother/baby dyad
2. Enables mother and family to make choices about behaviour change
3. Communicated to family doctor, Well Child visiting nurse, and to hospital health record

Send to DHB

Print

Email

Close

SUDI Protection Plan for low risk Baby

SUDI is sudden unexpected death in infancy, also known as SIDS or cot-death

Baby's risk of SUDI is Medium-Low.

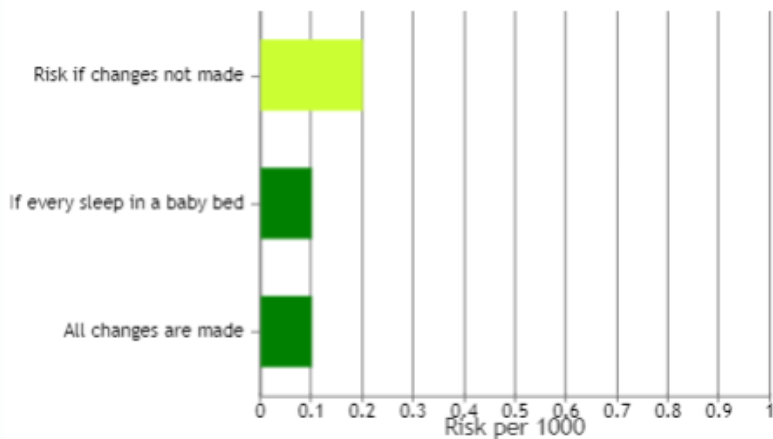
You and your family can make changes that can reduce your baby's risk to Low.

You and your family are already protecting baby by:

- ✔ **Breastfeeding** - it's best for baby. Continue to breastfeed your baby for at least 6 months and beyond.
- ✔ **Room sharing** means you are nearby if baby needs you.

Continuing to be:

- ✔ **Alcohol-free.** Remember a sober adult needs to look after your baby if you decide to drink. Plan ahead.
- ✔ **Drug-free.** Remember a drug free adult needs to look after your baby if you decide to use drugs. Plan ahead.
- ✔ **Smoke-free is best for baby**
Being smoke-free during pregnancy and in the home and car is very important for baby's SUDI protection, but also for you and your baby to be healthy now and in the future.



Confident conversations: How about the bed-sharing?

Mother age 29 years, BW 3600, baby girl, breastfed, 2 siblings, sleeping on back, bed-sharing.

Quick referrals to wrap-around services

Key-worker model & Wrap-around services:

1. WellChild nurse
2. Baby bed
3. Smoking cessation
4. Breastfeeding support
5. Immunisation
6. Healthy Housing
7. Parenting support
8. Cultural support
9. Mental health
10. Contraception

Mother/Babies **SUDI Protection Care - Mother** SUDI Protection Care - Baby Non-BF

SUDI Risk Assessments

No risk assessments recorded

SUDI Protection Care Required:

- Breastfed baby, if able.
- Sleep baby in their own baby bed (Wahakura, Pepi-pod, bassinet, cot)

Care Plan	Status
Safe-sleep baby bed	Requested from Raukura Hauora O Tainui Mokopuna Ora- tuku Manurewa Current status: Requested (07/10/2019)
Smokefree	Not Actioned
Healthy Housing	Requested from AWHI (National Hauora Coalition) tuku Current status: Requested (07/10/2019)
Breastfeeding support	Current to Service Te Rito Ora
Parenting Support	Not Actioned
Fanau Ola Pacific Health Support	Not Actioned
Maternal mental health services	Not Actioned
Contraception	Not Actioned
Whanau Ora	Not Actioned
Homecare Nurses	Not Actioned

Implementation Outcomes:

1. Proportion of birth cohort with safe sleep calculator assessment
2. Proportion of higher risk infants referred for SUDI wrap-around-care pathway
3. Proportion of infants at higher risk ($\geq 0.3/1000$) completing SUDI wrap-around-care

SUDI Prevention Care Programme Outcomes

1. Measurement of pre and post implementation individual level modifiable SUDI factors (sleep position, bed-sharing, non-room sharing, non-breastfeeding, non-immunization, maternal smoking, paternal smoking, maternal alcohol and drug use).

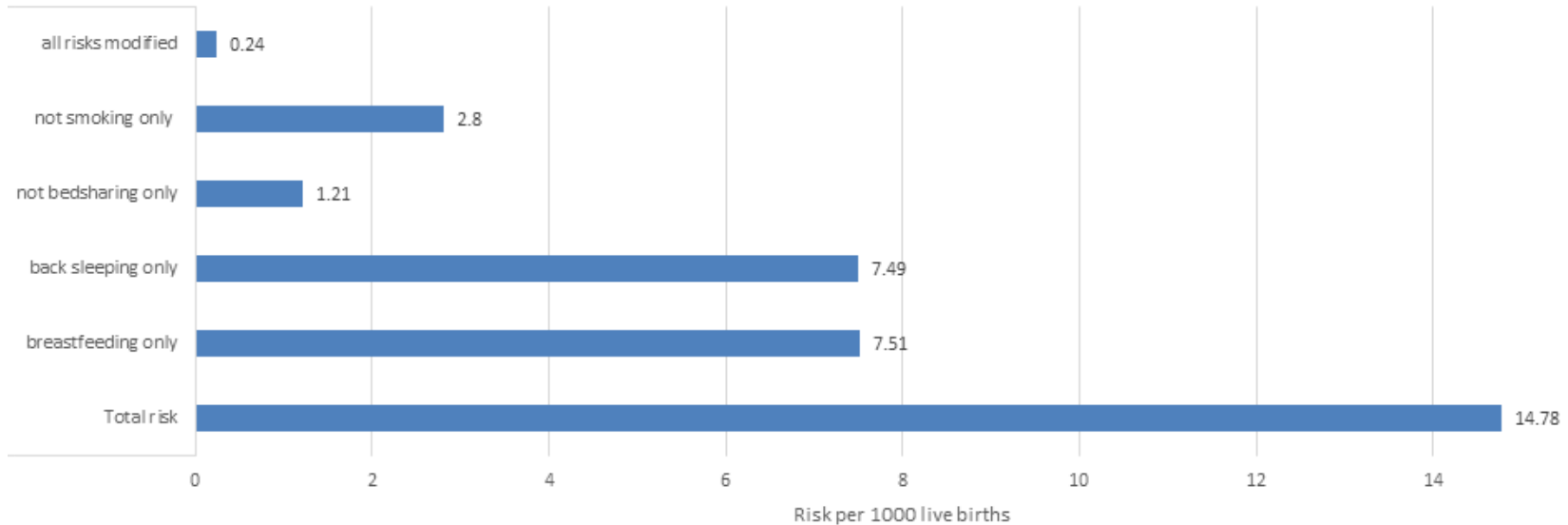
Key Points

- SUDI messages are complex because SUDI risk is complex
- The Safe Sleep Calculator
 - Objective
 - Targeted SUDI protection appropriate for population 'at risk'
- Behaviour change conversation is critical



How about Kate and her baby Sam?

Risk at birth for infant for mother aged 22 years, first baby, single, male infant, birthweight 2850g, not breastfeeding, bed sharing, baby side sleeping, mother smokes, no alcohol or drugs.



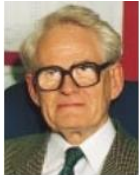
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