What Lessons can be Learned from Listening to Mothers?

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Boston University School of Public Health
BMC Grand Rounds
January 17, 2018



Presentation will involve both existing data and material from unpublished studies.

Slides not involving unpublished data will be posted and available to download for free at:

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First, brief context on Maternal Mortality in the U.S.

Definitions (in the U.S.)

- Maternal Mortality Ratio the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes. Typically reported as a ratio per 100,000 births.
- Pregnancy Related Death the death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.
- Pregnancy Associated Death The death of a women while pregnant or within one year of termination of pregnancy, irrespective of cause. (WHO calls these "pregnancy related")

Trends in Maternal Mortality:

Country and

territory

Kingdom

Republic of

United States

of America

Uzbekistan

Uruguay

Tanzania

United

United

1990 to 20	715					
Estimates by WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division						
	Range of MMR uncertainty (UI 80%)					

MMR^b

9

398

14

36

Lower

estimate

8

281

12

11

20

Upper

estimate

11

570

16

19

65

Lifetime risk of maternal death:d 1 in

5 800

45

3 800

3 300

1 000

Number of

maternal

deathsc

8 200

550

240

74

% of AIDSrelated indirect maternal deathse

2.4

Range of PM

uncertainty (UI 80%)

Lower

estimate

0.6

13.0

0.7

0.7

1.2

PM

8.0

18.4

8.0

0.9

2.2

Upper

estimate

0.9

26.3

0.9

1.2

4.0

Trends in

United Republic of

United States of

Tanzania

America

Uruguay

Uzbekistan

Maternal Mortality: 1990 to 2013)

Estimates by WHO, UNICEF, UNFPA, The World Bank and the United Nations Population Division

410

28

14

36

Country	MMK	_	of MINIK tainty	maternal deaths ^a	risk of maternal	% of AIDS- related indirect	- PIVI° (%)	Group
		Lower estimate	Upper estimate		death: ^a 1 in:	maternal deaths ^b		
United Kingdom	8	5	12	60	6900		0.6	Α

7900

1200

220

44

1800

3500

1100

5.9

13.3

1.5

8.0

2.2

Α

Α

660

44

20

42

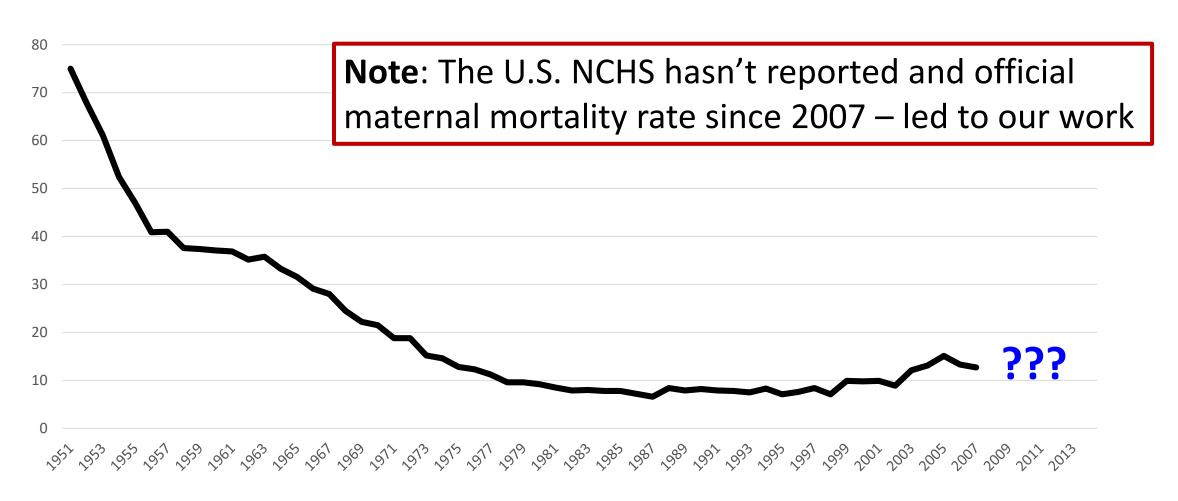
250

18

9

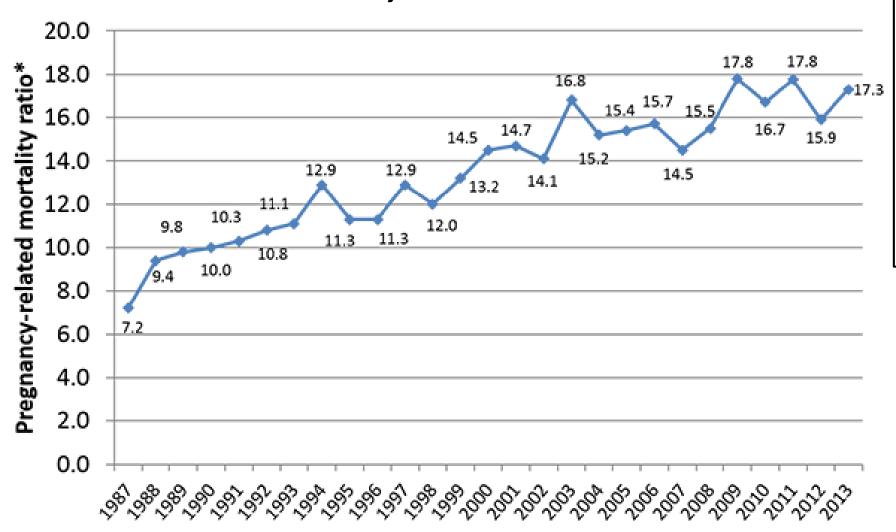
31

U.S. Maternal Mortality (per 100,000 live births), 1951-2007



Source: NCHS. Deaths: Final Data. Annual Reports.

Pregnancy Related Mortality, U.S., 1987-2013



^{*}Note: Number of pregnancy-related deaths per 100,000 live births per year.

Racial Disparities

Rates for 2011-13:

12.7 white women

43.5 black women

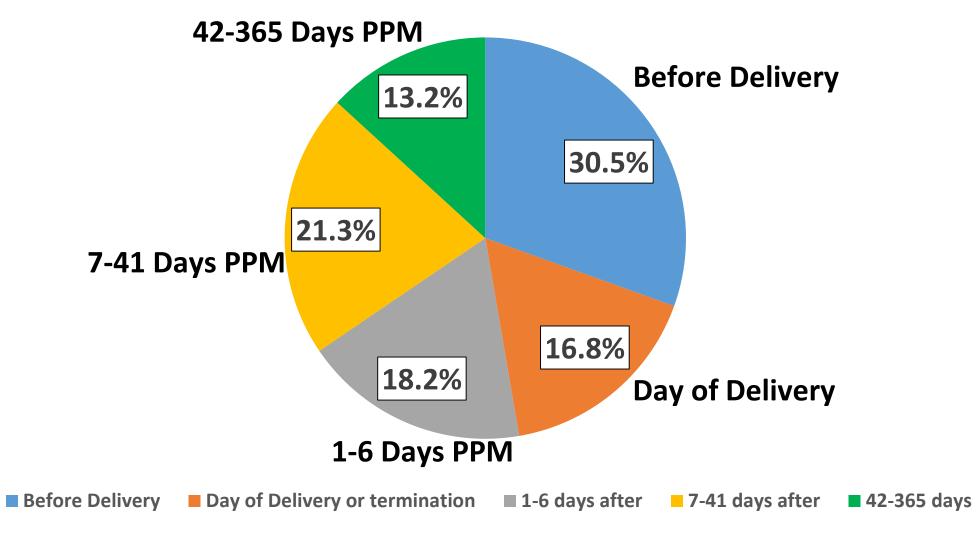
11.0 Hispanic

14.4 other races

Source: CDC.

Creanga. Pregnancy-Related Mortality in the United States. *Obstet Gynecol 2017*.

Timing of Maternal Deaths



Source: Creanga A et al. Pregnancy Related Mortality in the U.S., 2011-2013. Obstet & Gynec 2017.

Estimating Maternal Mortality Ratios

Adjusting the CDC Pregnancy Related Mortality data to reflect a maternal mortality rate

Estimated for 2011-2013 (per 100,000 live births):

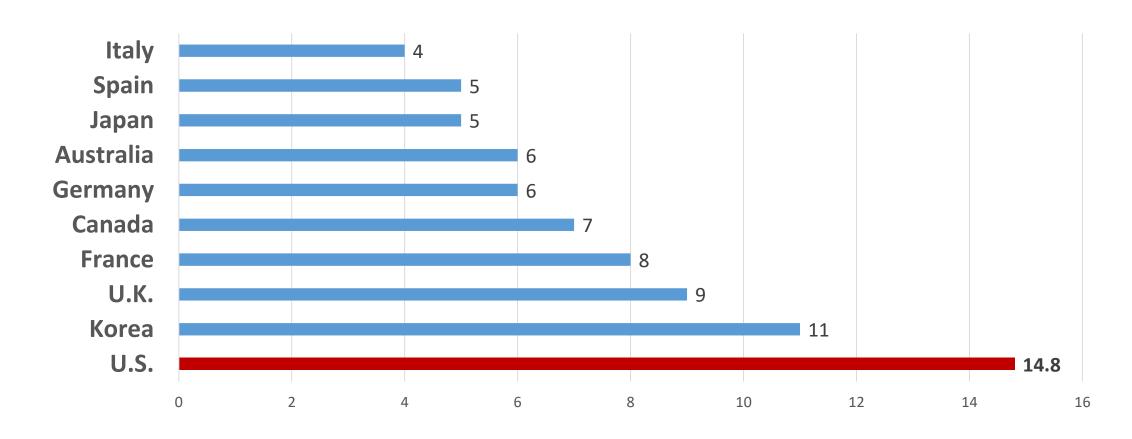
- All women
- Non-Hispanic white women
- Non-Hispanic black women
- Hispanic women

14.8 11.3 36.2 10.0

Black-white disparity

3.2

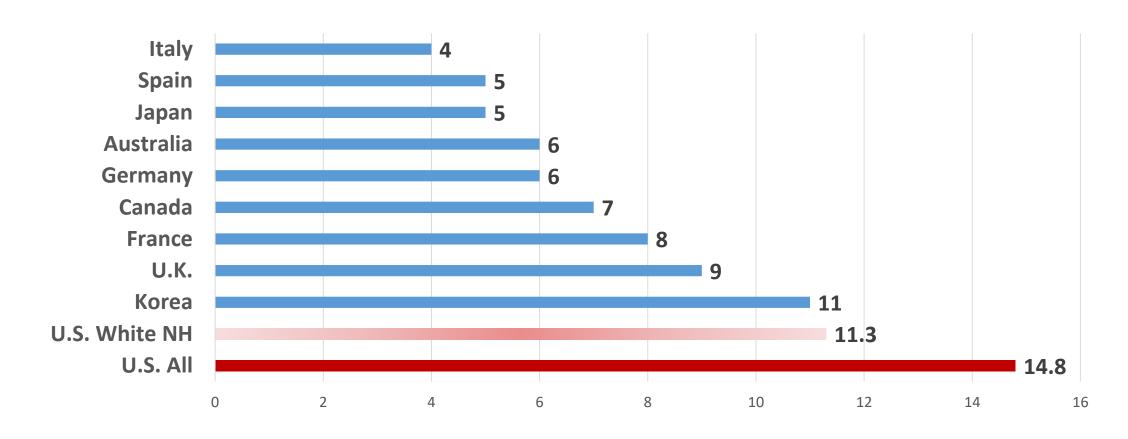
U.S. MMR* Compared to Countries with 300,000+ births, 2014, using WHO Estimates



* Maternal Mortality per 100,000 births

Source: Maternal Mortality: 1990 to 2015 Estimates by WHO, UNICEF, UNFPA, World Bank Group & UN Population Division. Geneva: 2015.

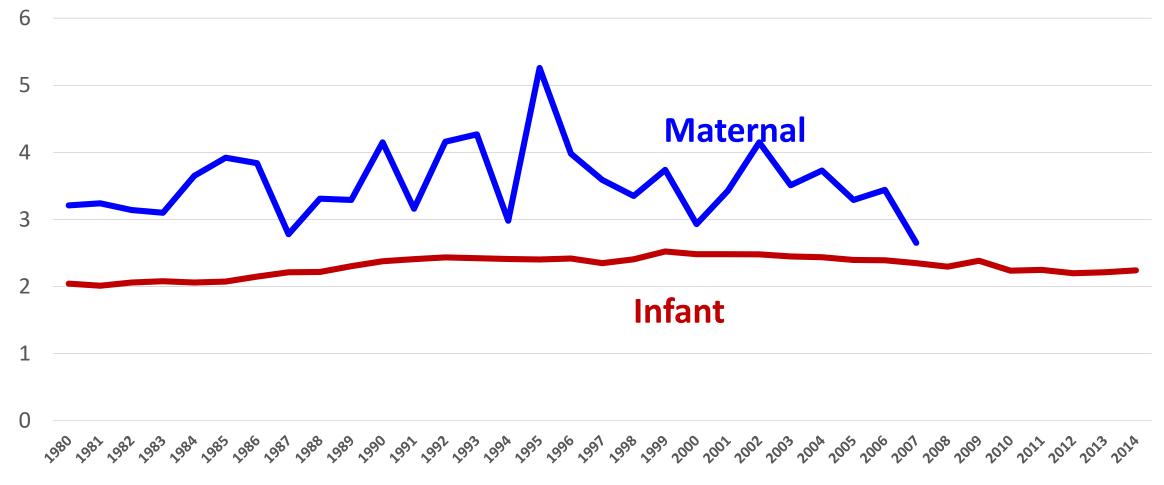
U.S. MMR* Compared to Countries with 300,000+ births, 2014, using WHO Estimates



^{*} Maternal Mortality Ratio per 100,000 births

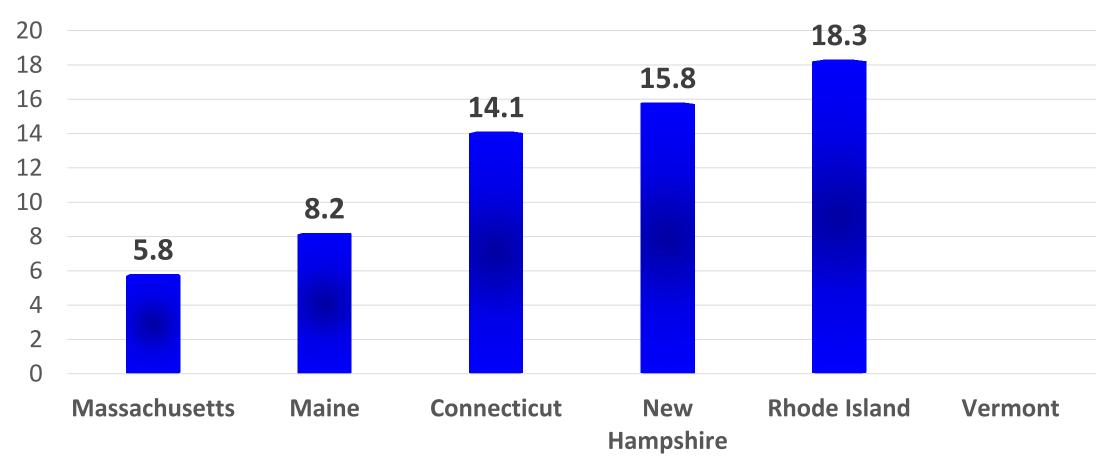
Source: Maternal Mortality: 1990 to 2015 Estimates by WHO, UNICEF, UNFPA, World Bank Group & UN Population Division. Geneva: 2015.

U.S. Infant & Maternal Mortality Black to White Ratios of 1980-2014



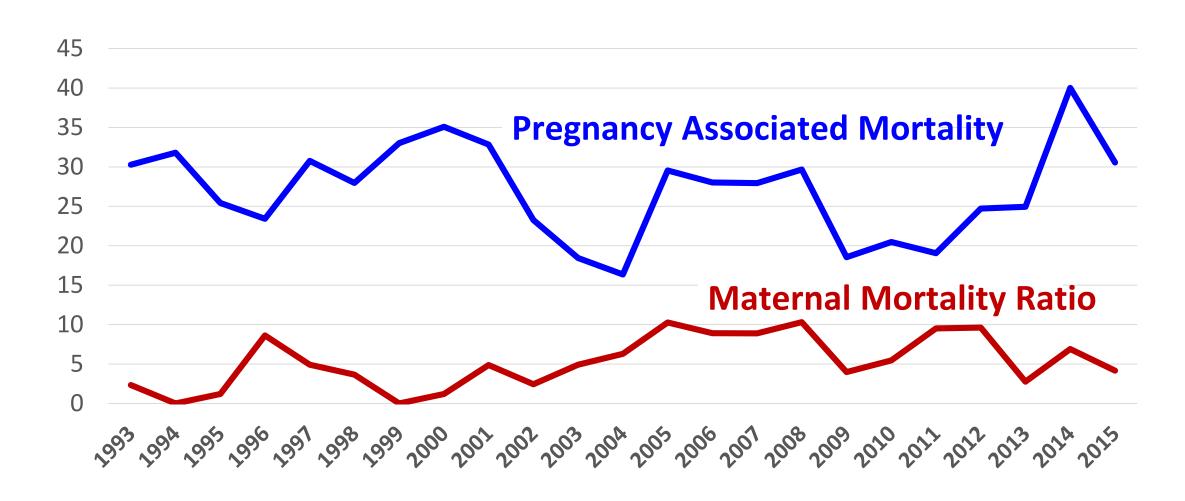
Why is disparity greater for maternal mortality than infant mortality?

Maternal Mortality Ratio (per 100,000 live births) in New England States, 2016 (?)



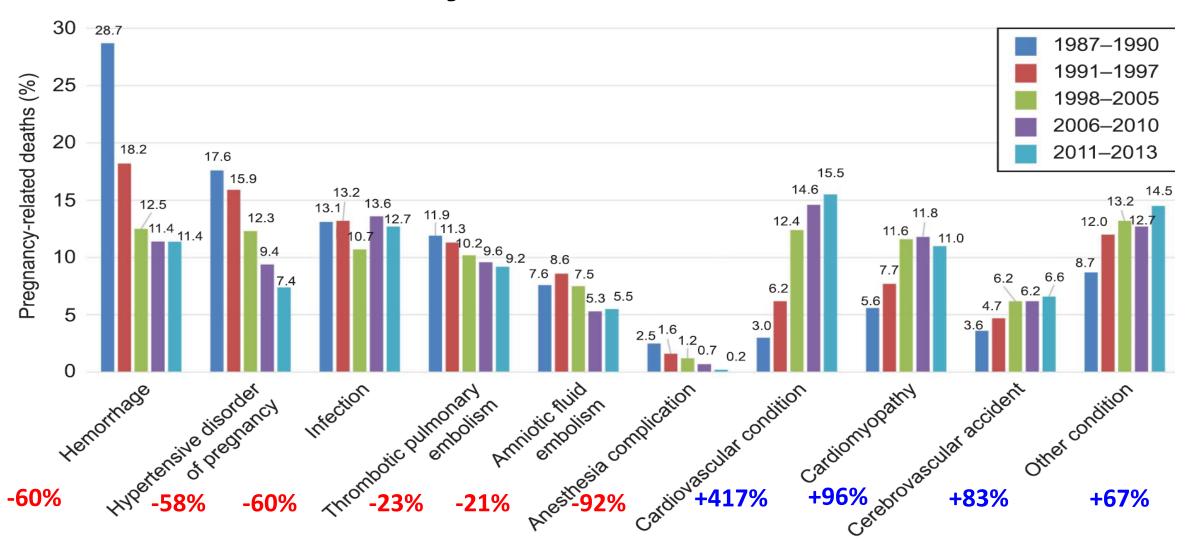
Source: America's Health Rankings. United Health Foundation. Their cited source – CDC, National Vital Statistics System <a href="https://www.americashealthrankings.org/explore/2016-health-of-women-and-children-report/measure/maternal mortality/state/CT/compare/RI to the compare of the compa

Massachusetts Maternal Deaths, (per 100,000), 1992-2015



Source: Mass DPH

Cause-specific proportionate pregnancy-related mortality: United States, 1987–2013.



Source: Creanga. Pregnancy-Related Mortality in the United States. Obstet Gynecol 2017.

Turning now to the actual topic of this presentation

Why It's Important to Listen to Mothers

- Humbling because we find that they don't think like we do
- Maternal Attitudes Determine mothers' attitudes toward pregnancy, birth and the postpartum experience
- Mothers' Perspectives Document mothers' experience from their perspective
- Identify needs and who has them that wouldn't be known from other data sources
- Can get at the "Why?" question which is not possible from other sources which focus on "What?"
- Leads to better Design of Systems and better Outcomes

So what can we learn from mothers that we can't learn from other sources?

Listening to Mothers III Pregnancy and Birth



Report of the Third National U.S. Survey of Women's Childbearing Experiences



Eugene R. Declercq Carol Sakala Maureen P. Corry Sandra Applebaum Ariel Herrlich

May 2013

Listening to Mothers" III New Mothers Speak Out



Report of National Surveys of Women's Childbearing Experiences Conducted October - December 2012 and January - April 2013



Eugene R. Declercq Carol Sakala Maureen P. Corry Sandra Applebaum Ariel Herrlich

June 2013

California Listening to Mothers just back from the field

Survey Data

- 2400 mothers 18-45 who had given birth to single babies in a U.S. hospital from July 1, 2011 through June 30, 2012 completed the 30 minute survey online in English.
- The data were adjusted with demographic and propensity score weightings using methodology developed and validated by Harris Interactive with results generally representative of U.S. mothers on age, race/ethnicity, parity, birth attendant and mode of birth.
- Mothers who completed the initial survey were recontacted and invited to complete a follow-up survey between January 29 and April 15, 2013. A total of 1072 mothers, or 45% of the initial participants, were reached and completed the survey.

What can we learn from mothers that we can't learn from other sources?

1. Careful, accurate prenatal diagnosis

(The case of the "Big Baby")

2. Choice in the Place of Birth

3. Choice in Method of Delivery

(The case of the vanishing VBAC)

What can we learn from mothers that we can't learn from other sources?

4. Opportunity for Shared decision making (Induction and repeat cesareans)

5. Experience of Poor Treatment

Bonus Material!

1. Careful, Accurate Prenatal Diagnosis

I would like my maternity care provider to tell me about the risks associated with each option so I know how each could affect me.

Strongly Agree	36%
Agree	55%
Disagree	7%
Strongly Disagree	2%

Source: Listening to Mothers 3

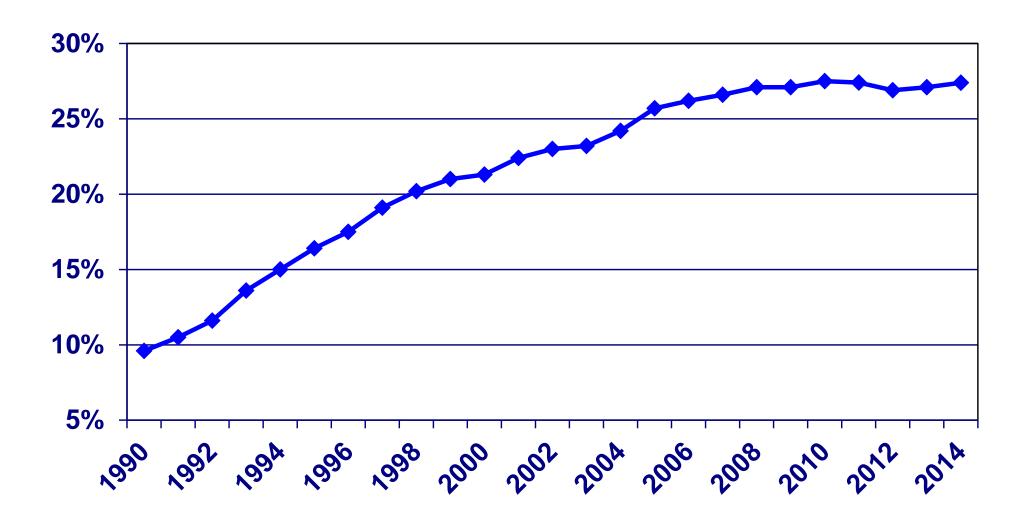
1. Careful Accurate Prenatal Diagnosis The rise of the big baby



The rise of the big baby



Inductions in Vaginal Births, U.S., 1990-2014



Source: Centers for Disease Control and Prevention. National Center for Health Statistics. VitalStats. http://www.cdc.gov/nchs/vitalstats.htm.

BirthByTheNumbers.org

Labor Induction – Listening to Mothers

- Three in ten (29%) mothers tried to start their labor on their own.
- More than four out of ten respondents (41%)
 indicated that their care provider tried to induce
 their labor
- Three out of four of those women (74%) indicating that it did start labor, resulting in an overall rate of medically induced labor of 30%.

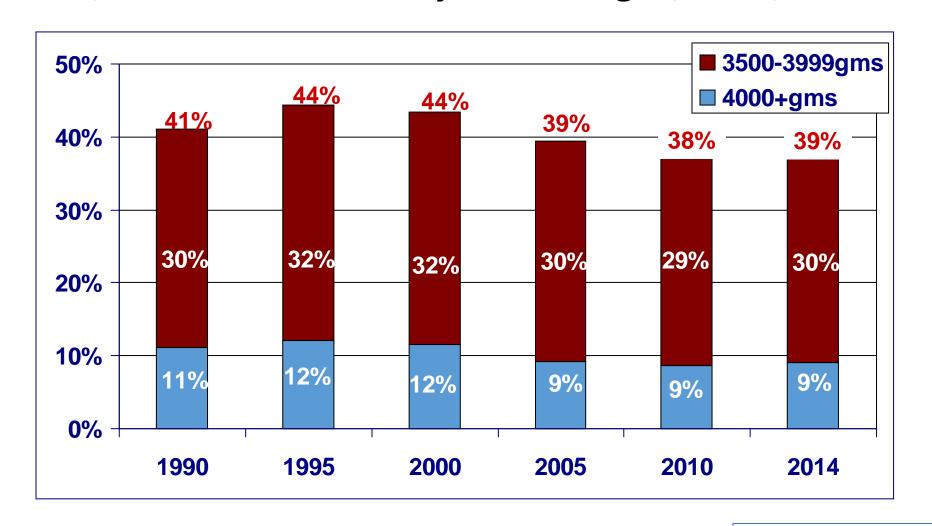
Reasons why mothers experienced medical induction

Base: care provider tried to induce labor <i>n</i> =991		
Baby was full term/close to due date	44%	
Mother wanted to get pregnancy over with	19%	
Care provider was concerned that mother was "overdue"	18%	
Maternal health problem that required quick delivery	18%	
Care provider was concerned about the size of the baby		
Water had broken and there was a concern about infection	12%	
Mother wanted to control timing of birth for work or other personal reasons	11%	
Care provider was concerned that amniotic fluid around the baby was low	11%	
Care provider was concerned that baby was not doing well	10%	
Mother wanted to give birth with a specific provider	10%	

Reasons for primary and repeat cesarean birth

Base: had cesarean n=744 (choose reason that best applies)	Primary cesarean	Repeat cesarean n=376
I had had a prior cesarean (asked of prior cesarean only)	n.a.	61%
Baby was in the wrong position	16%	3%
Fetal monitor showed the baby was having problems during labor	11%	3%
I had a health condition that called for procedure	10%	13%
Baby was having trouble fitting through	10%	2%
Maternity care provider worried the baby was too big		2%
Provider tried to induce labor but it didn't work		3%
Problem with the placenta	8%	2%
Labor was taking too long	7%	2%
Past my due date	3%	-
Afraid to labor and have baby vaginally	3%	-
No medical reason	4%	3%

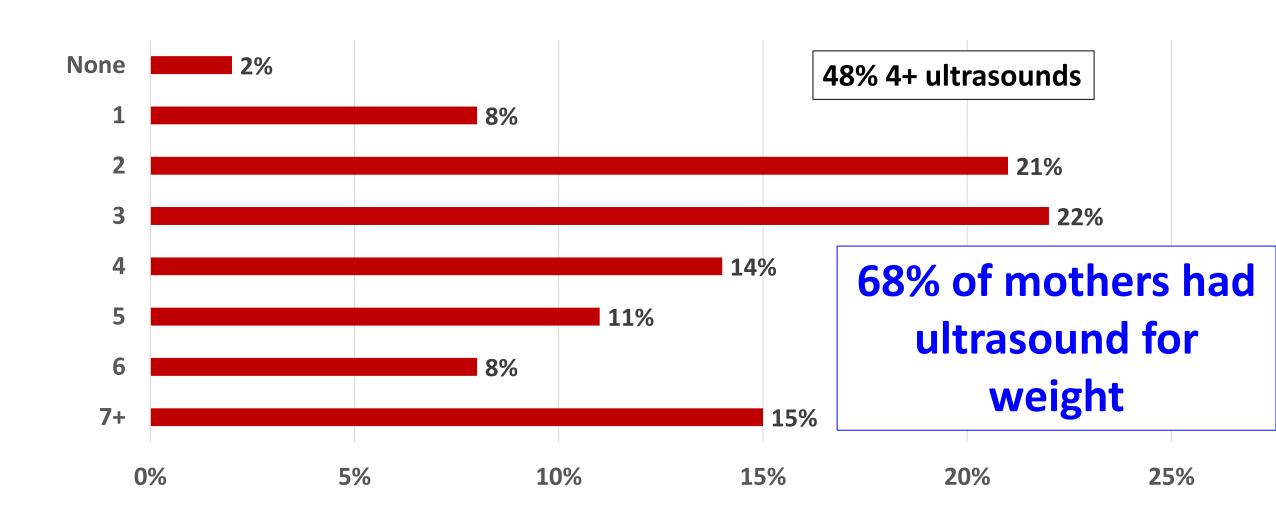
Are U.S. Babies Getting Bigger?...NO! % Singleton, Full Term Babies by Birthweight, U. S., 1990-2014



Source: Centers for Disease Control and Prevention.

www.BirthByTheNumbers.org

Number of Ultrasounds



Labor and Delivery Experiences of Mothers with Suspected Large Babies

Erika R. Cheng¹ · Eugene R. Declercq² · Candice Belanoff³ · Naomi E. Stotland⁴ · Ronald E. Iverson⁵

What's with these Big Babies?

Near the end of your pregnancy, did your maternity care
provider tell you that your baby might be getting quite large?

31.2% YES	ALL	Yes	No	
Actual Weight	7 lbs	7 lbs	7 lbs	
	5 ounces	14 ounces	1 ounce	
Baby Macrosomic (8lb 13ounces)	9.9%	19.7%	5.5%	

Source: Cheng et al. Healthcare Utilization of Mothers with Suspected Large Babies. MCH Journal. 2015. 19:2578–2586

What's the impact of being told you might have a big baby?

Labor and Delivery Outcomes

	Suspecte		
	<u>Yes</u>	<u>No</u>	
	<u>%</u>	<u>%</u>	
Tried Self Induction of Labor	43.0	24.7	***
Medical Induction of Labor	70.1	51.1	***
Cesarean Delivery	21.1	18.1	NS
Epidural Analgesia	72.7	61.7	***
Requested Cesarean	22 5	<i>C</i> 0	***
Delivery	32.5	6.8	Ale ale

^{***}p < .001

BirthByTheNumbers.org

Likelihood of Labor or Delivery Outcomes Controlling for Key Variables

Self Induced Labor – almost twice as likely

Medical Induction – almost twice as likely

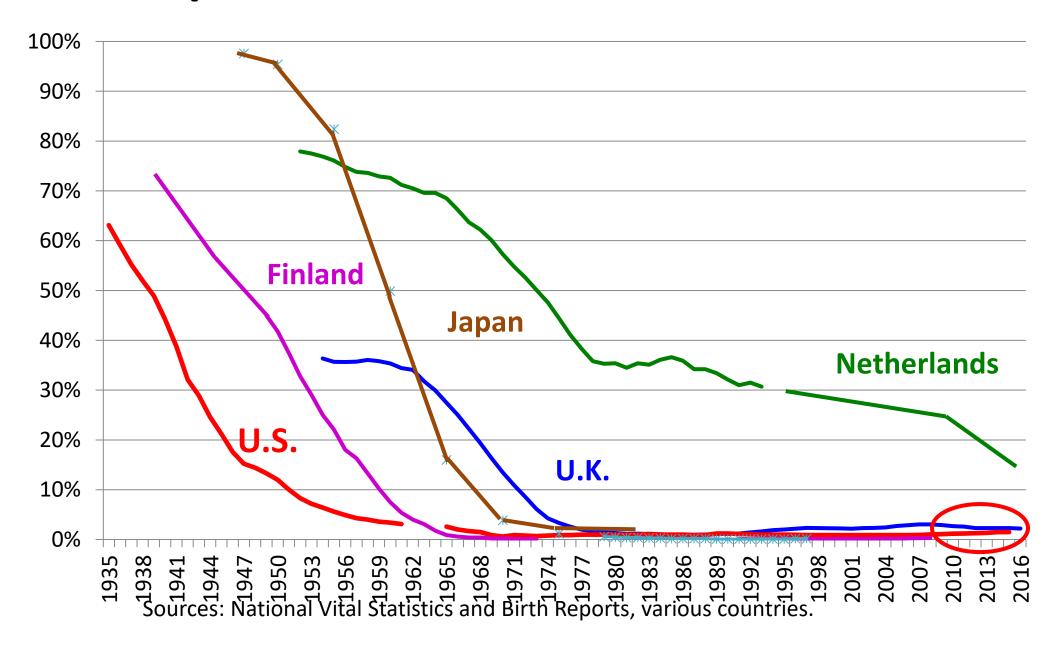
Epidural – twice as likely

Requesting a cesarean – 4 times as likely

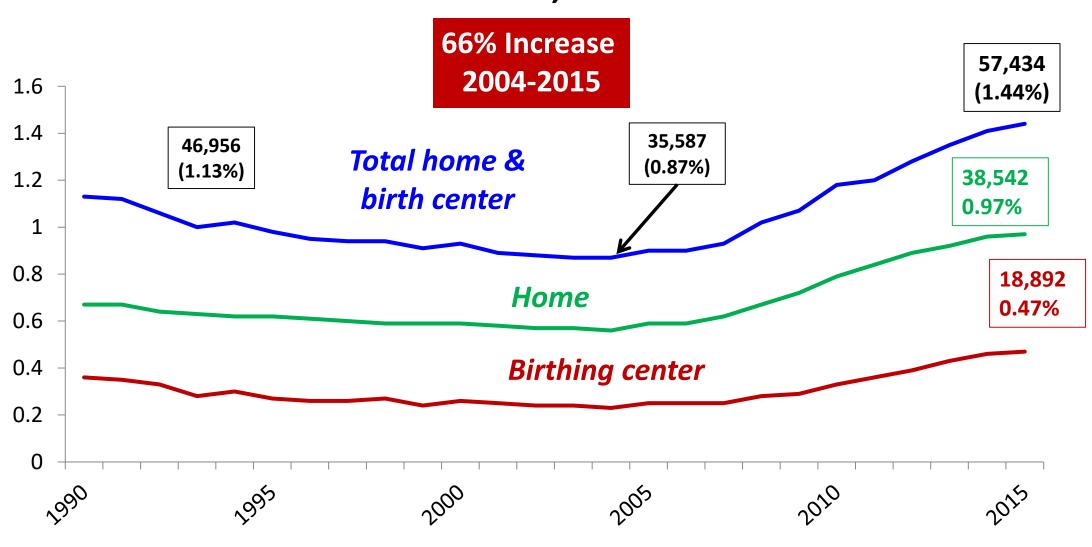
Would have never discovered this phenomenon if we didn't listen to mothers

2. Mothers' Interest in Alternatives for Place of Birth

Out of Hospital Births, Selected Countries, 1935-2016



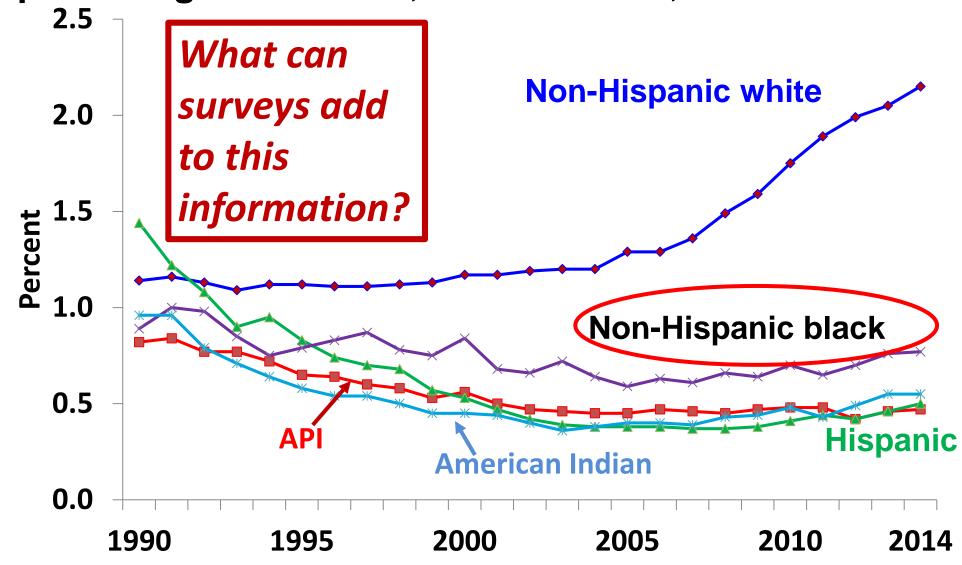
Percent of all births at home, or in a birthing center, United States, 1990-2015



Source: NCHS Annual Birth Reports & CDCVitalStats. http://www.cdc.gov/nchs/nvss.htm

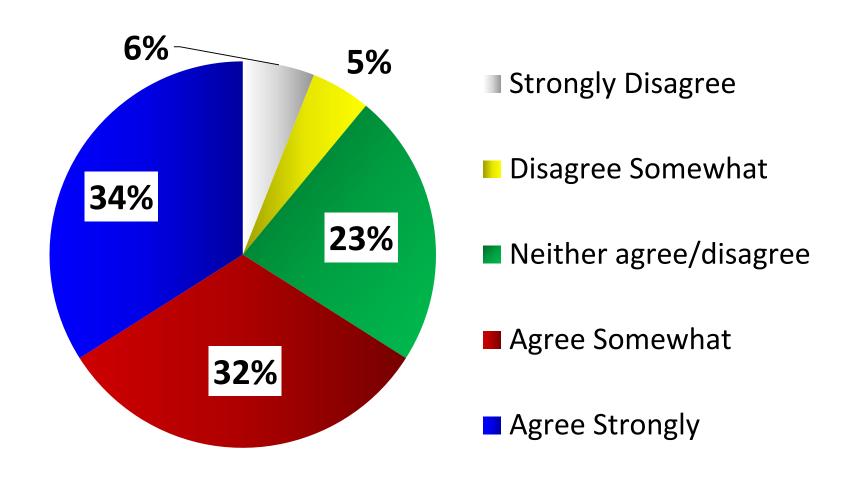
BirthByTheNumbers.org

Percentage of births occurring outside a hospital by race and Hispanic origin of mother, United States, 1990-2014

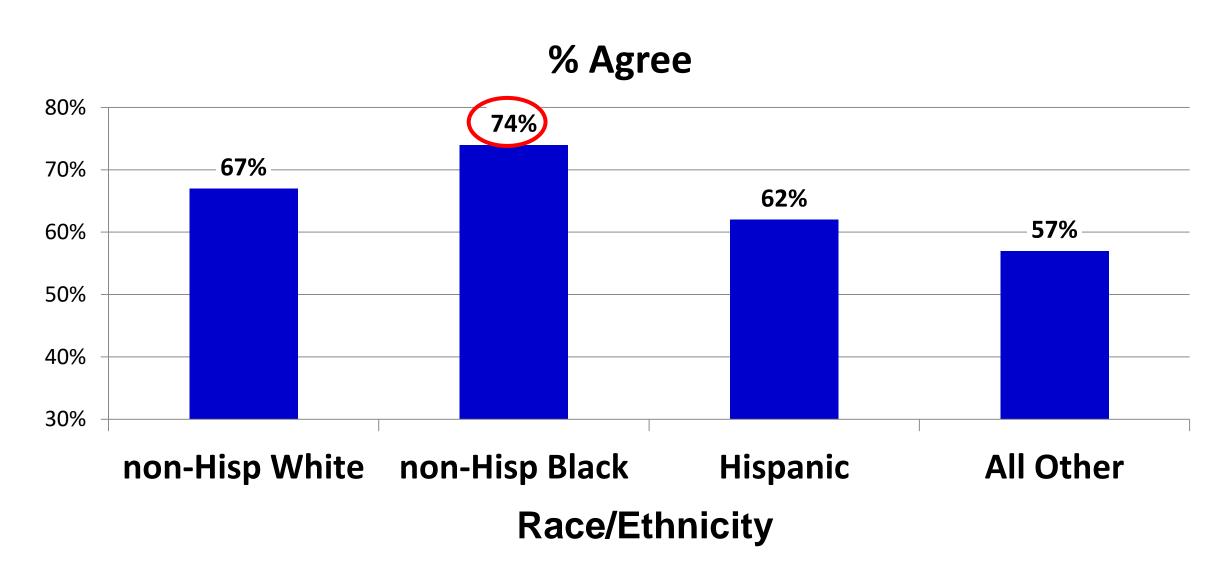


Notes: Non-Hispanic white, Non-Hispanic black and Hispanic data exclude New Hampshire in 1990-92 and Oklahoma in 1990, as these states did not report. Hispanic origin on their birth certificates for those years. API denotes Asian or Pacific Islander. Source: Birth certificate data from the National Vital Statistics System.

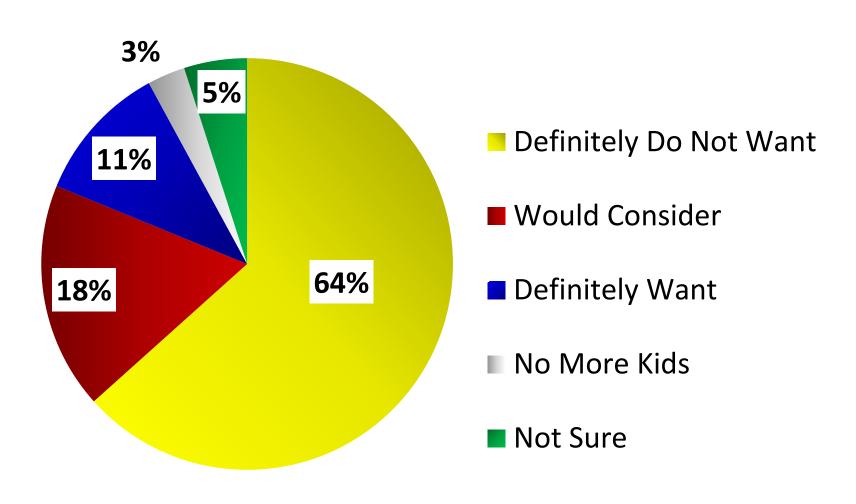
If a woman wants to have her baby at home, she should be able to do so.



If a woman wants to have her baby at home, she should be able to do so.

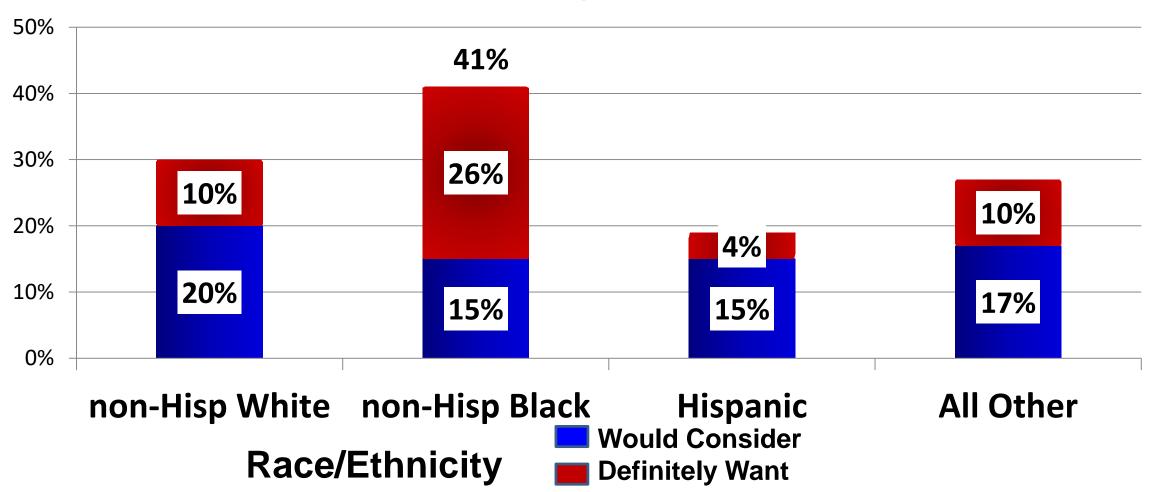


For any future births, how open would you be to giving birth at home?



For any future births, how open would you be to giving birth at home?

% Agree



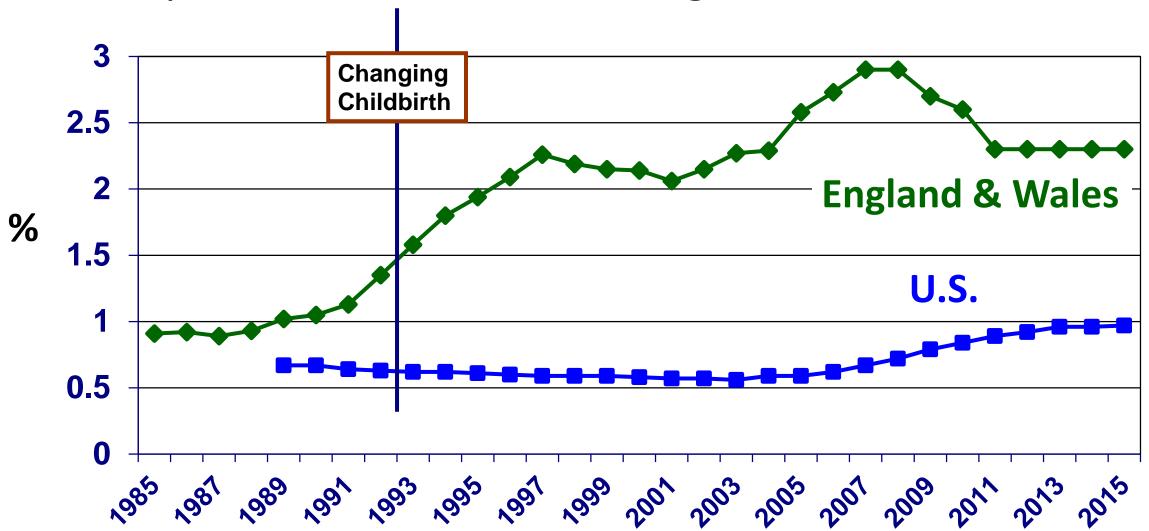
 So home births are really rising in the U.S. and some industrialized countries.

In absolute numbers there are more home births in the U.S. than in the Netherlands.

This trend will keep going right?

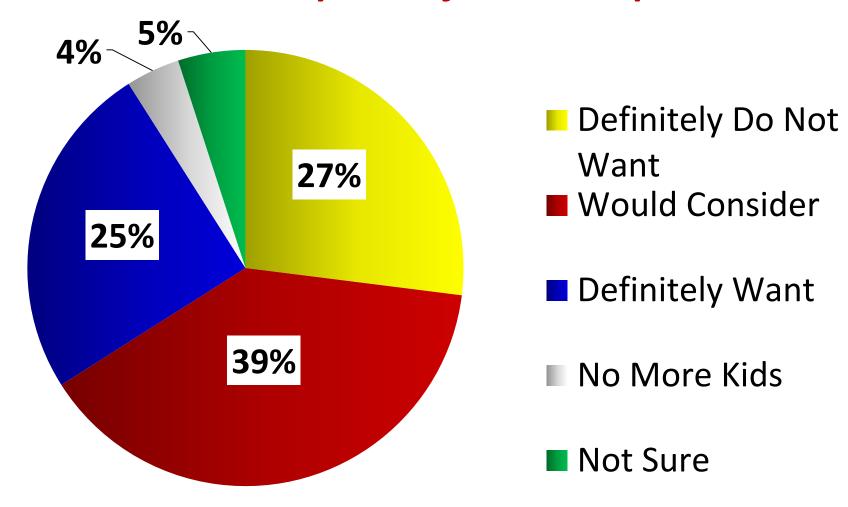
Not too much more

Proportion of Home Births, England, U.S., Australia



EVEN GREATER INTEREST IN BIRTH CENTERS

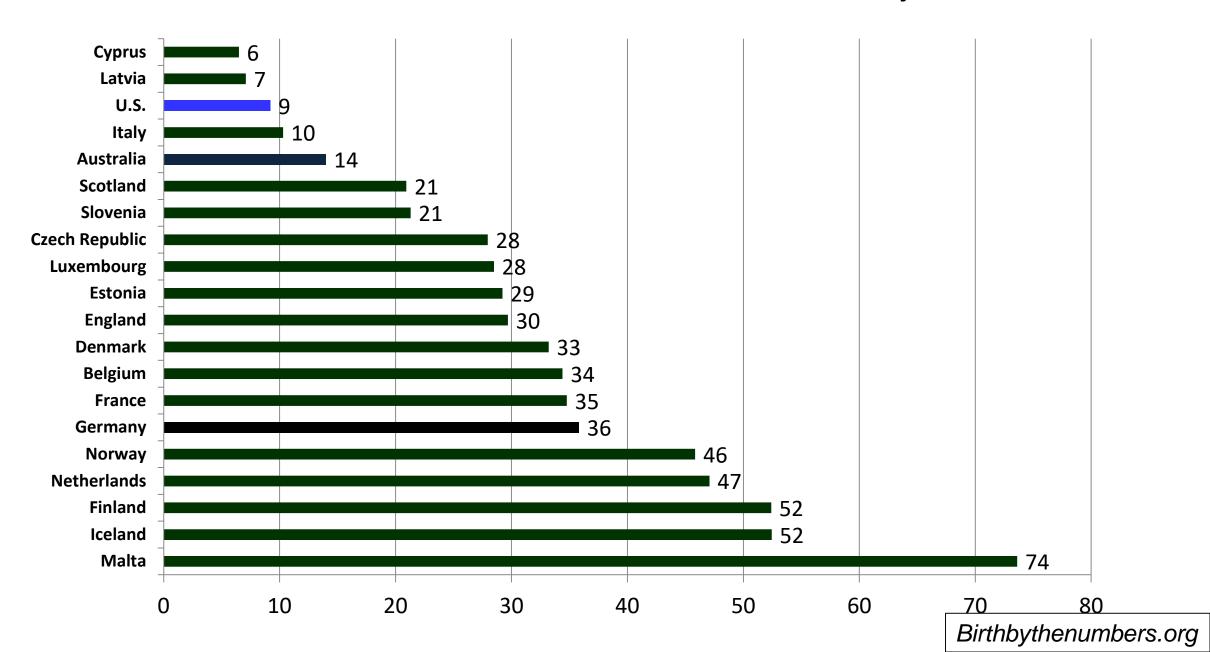
For any future births, how open would you be to giving birth at a birth center that is separate from a hospital?



3. Choice in Method of Delivery

Mothers' Experience with Vaginal Birth After Cesarean

VBAC Rates Industrialized Countries, 2010



Bulletin followed an NIH Consensus Meeting and Publication of Evidence Report

THE AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS

WOMEN'S HEALTH CARE PHYSICIANS



PRACTICE BULLETIN

CLINICAL MANAGEMENT GUIDELINES FOR OBSTETRICIAN—GYNECOLOGISTS

Number 115, August, 2010

(Replaces Fractice Bulletin Number 34, July 2004 and Committee Opinion Number 342, August 2006), Reaffirmed 2013 Committee on Practice Bulletins—Obstetrics. This Practice Bulletin was developed by the Committee on Practice Bulletins—Obstetrics with the assistance of William Grobman, MD, and Jeffrey Ecker, MD. The information is designed to aid practitioners in making decisions about appropriate obstetric and gynecologic care. These guidelines should not be construed as dictating an exclusive course of treatment or procedure. Variations in practice may be warranted based on the needs of the individual patient, resources, and limitations unique to the institution or type of practice.

PDF Format

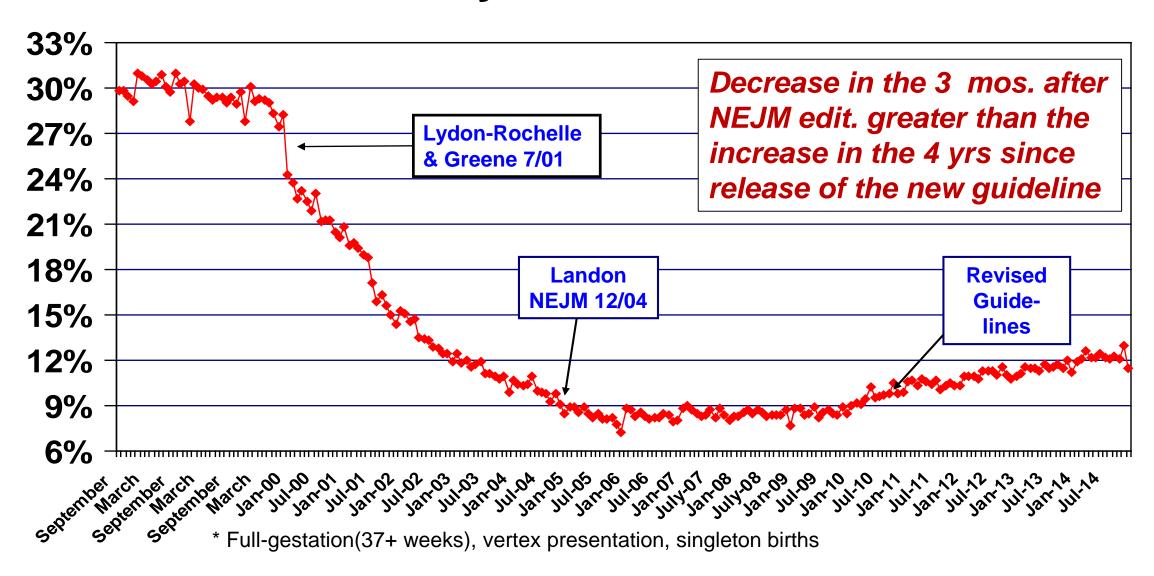
Vaginal Birth After Previous Cesarean Delivery

Summary of Recommendations

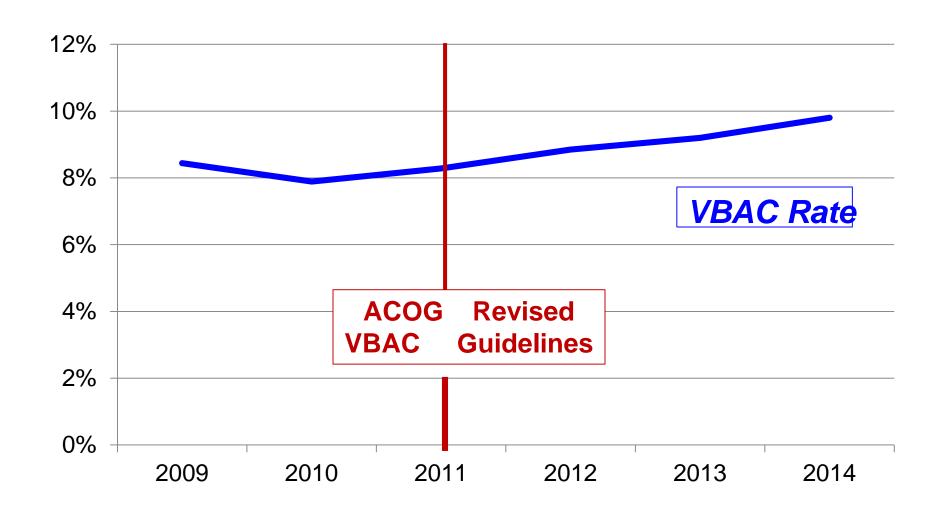
The following recommendations are based on good and consistent scientific evidence (Level A):

Most women with one previous CD with a low-transverse incision are candidates for and should be counseled about VBAC and offered TOLAC.

% VBAC Lower Risk* Mothers, U.S., Monthly Rates, 2000-2014



VBAC Rate Low Risk Births*, 28 States with revised Birth Certificate, 2009-2014



^{*} Singleton, Vertex, Gest Age 37+ weeks, 1 cesarean.

If ACOG puts out new guidelines, why so little effect?

Try asking mothers

Mothers' Interest in and Access to VBACs

Base: had cesarean in the past and for most recent birth	LTMI 2000-02	LTMII 2005	LTMIII 2011-12
Was interested in the option of a vaginal birth after cesarean	n.a.	45%	48%
Did not have the option of a vaginal birth, or VBAC	42%	52 %	56%

New VBAC Guidelines

U.S. Mothers Report of Experience Seeking a VBAC, 2000, 2005, 2012

Mother had cesarean in the past, and did not have the option of a VBAC for recent birth.	LTMI 2000-02	LTMII 2005	LTMIII 2011-12
Did not have the option because caregiver was unwilling to do a VBAC	36%	45%	24%
Did not have the option because hospital was unwilling to allow a VBAC	12%	23%	15%
Medical reason unrelated to prior cesarean	38%	20%	45%

Source: *Listening to Mothers 3*.

New VBAC Guidelines

4. Opportunity for Shared decision making (Induction and repeat cesareans)

Decision-Making Process Reported by Medicare Patients Who Had Coronary Artery Stenting or Surgery for Prostate Cancer

Floyd J. Fowler Jr PhD^{1,2}, Patricia M. Gallagher, PhD¹, Julie P. W. Bynum, MD^{3,7}, Michael J. Barry, MD^{2,4}, F. Leslie Lucas, PhD⁵, and Jonathan S. Skinner, PhD^{6,7}

¹Center for Survey Research, University of Massachusetts Boston, Boston, MA, USA; ²Foundation for Informed Medical Decision Making, Boston, MA, USA; ³Department of General Internal Medicine, Dartmouth Hitchcock Medical Center, Hanover, NH, USA; ⁴General Medicine Division, Massachusetts General Hospital, Boston, MA, USA; ⁵Center for Outcomes Research, Maine Medical Center, Portland, ME, USA; ⁶Department of Economics, Dartmouth College, Hanover, NH, USA; ⁷The Dartmouth Institute, Dartmouth College, Hanover, NH, USA.

Original Investigation

How Patient Centered Are Medical Decisions? Results of a National Survey

Floyd J. Fowler Jr, PhD; Bethany S. Gerstein, BA; Michael J. Barry, MD

Patient Centered care requires....

"...... a partnership between the provider and the patient with shared power and responsibility in decision making and care management [and] giving the patient access to understandable information and decision support tools that help patients manage their health and navigate the health care delivery system."

Source: Department of Health and Human Services. National Strategy for Quality Improvement in Health Care. 2011.

Mothers' experiences of making labor & birth decisions

Induction mentioned because baby might be getting quite large.	n=163
How much did you and your maternity care provider talk about the reasons you <u>might want</u> to have an induction (% "some" or "a lot")?	61
How much did you and your maternity care provider talk about the reasons you <u>might not want</u> to have an induction (% "some" or "a lot")?	38
Did your maternity care provider explain that there were choices (% yes)?	82
Did your maternity care provider ask you whether or not you wanted to have (% yes)?	77
Did maternity care provider express opinion about whether or not you should have induction?	81
Did your maternity care provider think you should or should <u>not</u> have (% should have induction among those who expressed opinion)?	80
Who made the final decision whether or not to have induction?(% mother's /% MCP/% shared)?	46/20/34
If you knew then what you know now, do you think you would make the same decision about having (% definitely yes")?	64

Mothers' experiences of making labor & birth decisions

Repeat cesarean or VBAC decision for mothers with 1 or 2 prior CS. N= 321			
How much did you and your maternity care provider talk about the reasons you <u>might want</u> to have an induction (% "some" or "a lot")?	61		
How much did you and your maternity care provider talk about the reasons you <u>might not want</u> to have an induction (% "some" or "a lot")?	38		
Did your maternity care provider explain that there were choices (% yes)?	82		
Did your maternity care provider ask you whether or not you wanted to have (% yes)?	77		
Did maternity care provider express opinion about whether or not you should have induction?	81		
Did your maternity care provider think you should or should <u>not</u> have (% should have induction among those who expressed opinion)?	80		
Who made the final decision whether or not to have induction?(% mother's /% MCP/% shared)?	46/20/34		
If you knew then what you know now, do you think you would make the same decision about having (% definitely yes")?	64		

If this is a shared process how did so many mothers end up with the intervention?

Mothers' reported experience of pressure to have interventions, by whether mothers had intervention

Intervention	Experience of pressure among mothers who did not have intervention*	Experience of pressure among mothers who had intervention
Labor induction	8%	25%
Primary cesarean	7%	28%
Repeat cesarean	28%*	22%

^{*} Mothers having a VBAC

www.birthbythenumbers.org

5. Mothers' Reported Experiences with Discrimination

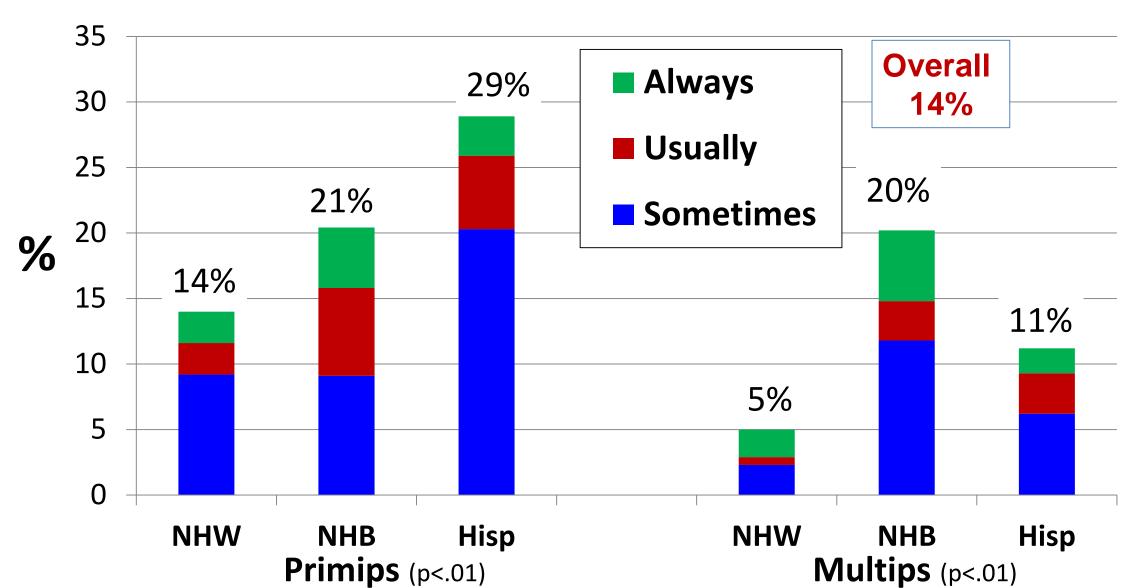
Mothers' experience of discrimination during childbirth hospital stay

During your recent hospital stay when you had your baby, how often were you treated poorly because of...?:

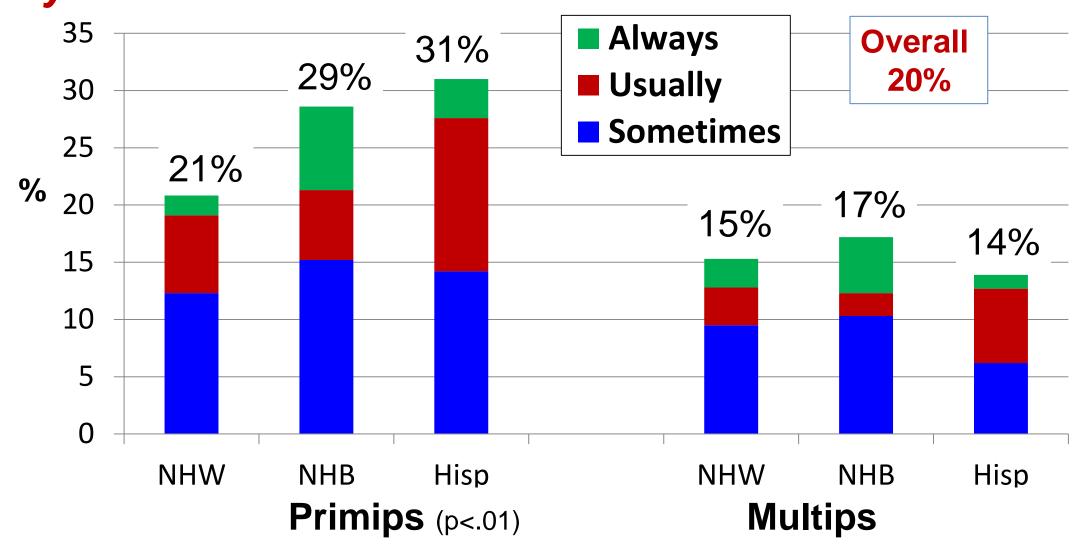
Base: all mothers n=2400	Never	Sometimes	Usually	Always	At Least "Some"
Your race, ethnicity, cultural background, or language	86%	8%	3%	3%	14%
Your health insurance situation	84%	8%	5%	4%	17%
A difference of opinion with your caregivers about the right care for yourself or your baby	80%	11%	6%	3%	20%

During your recent hospital stay when you had your baby, how often were you treated poorly because of

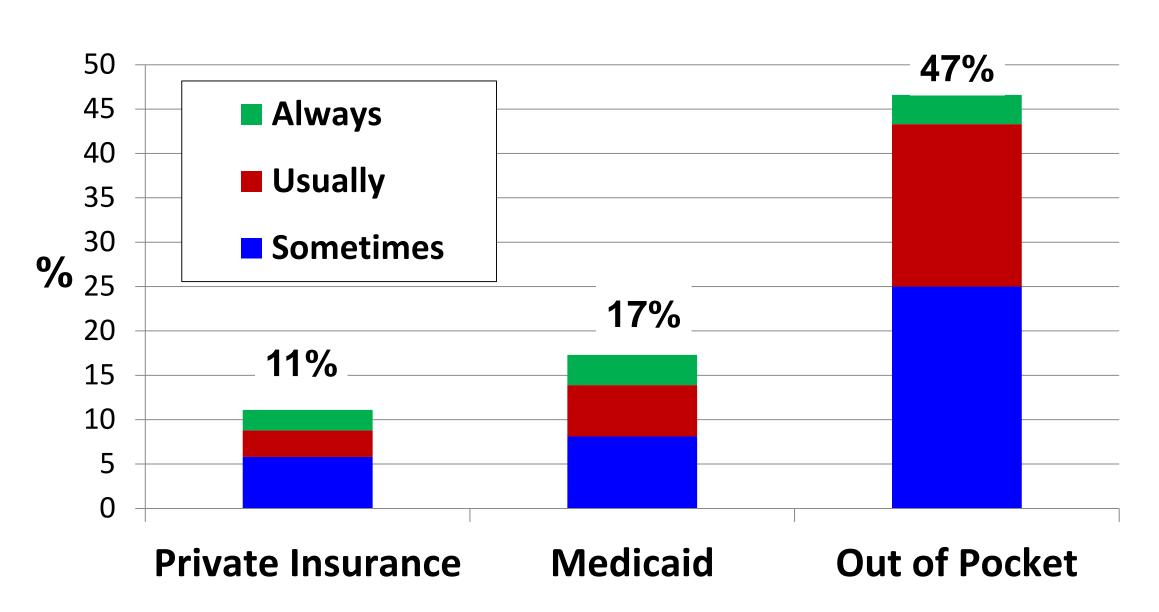
your race, ethnicity, cultural background or language?



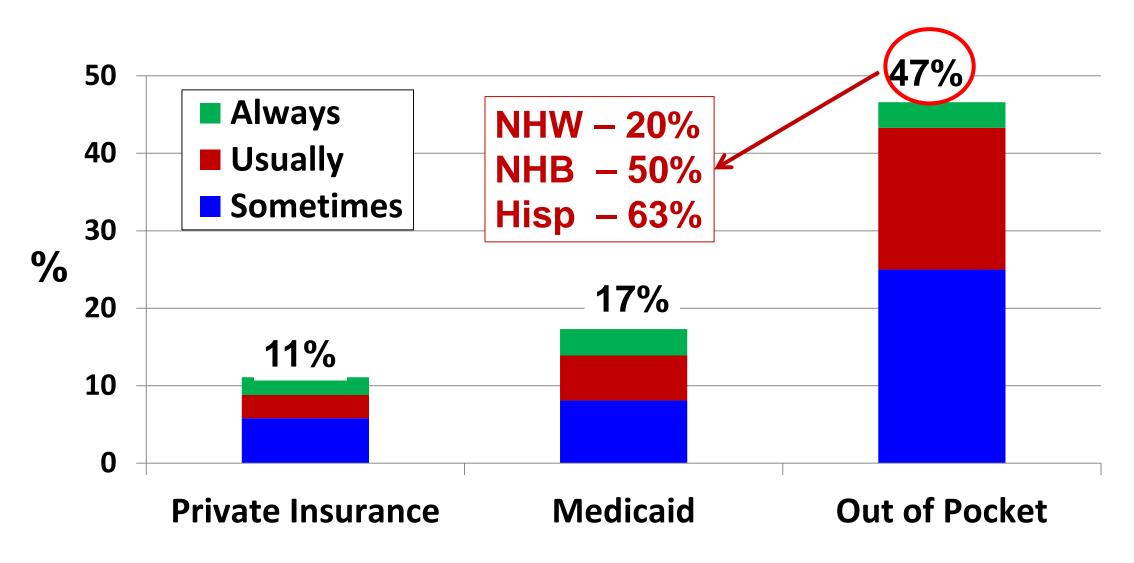
.....treated poorly because of a difference of opinion with your caregivers about the right care for yourself or your baby?



..... treated poorly because of your health insurance situation?



.....treated poorly because of your health insurance situation?



Bonus Insight!!

Trends in U.S. Mothers Attitudes toward Intervention in Birth

Trends in Mothers Attitudes toward intervention in birth

Birth is a process that should not be interfered with unless medically necessary	LTMI 2000-02 n=1583	LTMII 2005 n=1573	LTMIII 2011-12 n=2400
Disagree strongly or somewhat	31%	24%	16%
Neither agree nor disagree	24%	25%	26%
Agree somewhat or strongly	45%	50%	58%

NOTE: CA LtM ~ 74% agreement

