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*Helping women and health professionals make informed maternity care decisions*

# Health Care Consumer Views and Expectations- New Results from National "Listening to Mothers" Surveys Point to Need for More Comparative Effectiveness Research, Patient Engagement and Shared Decision Making

**Preconference Symposium: Comparative Effectiveness and Patients**

**Washington, DC, September 16, 2013**

**Maureen Corry, MPH**
**Executive Director**
**Childbirth Connection**



## Childbirth Connection

- Since 1918, working to improve maternity care quality on behalf of women and families
- Mission is to improve the quality of maternity care through consumer engagement and health system transformation
- Childbirth Connection promotes safe, effective and satisfying evidence-based maternity care and is a voice for the needs and interests of childbearing families

*Learn more: http://www.childbirthconnection.org/pdfs/90-year-timeline.pdf*

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## *Evidence-Based Maternity Care*

"Milbank Report" (2008), Evidence-Based Maternity Care: What It Is and What It Can Achieve, defines EBMC as effective care with the least harm

Report compared:

- systematic reviews of best available evidence about maternity practices impacting large proportion of women, newborns
- results of *Listening to Mothers II* survey of women who gave birth in U.S. hospitals in 2005 and other data sources

Found many evidence-practice gaps, overuse, underuse

*Sakala C and Corry MP. Evidence-Based Maternity Care: What It Is and What It Can Achieve. 2008. Available at: http://transform.childbirthconnection.org/resources/datacenter/*



## Evidence-Practice Gap in Maternity Care

Much of the care women receive is not consistent with the best evidence despite unprecedented body of comparative effectiveness research to guide maternity care research, education, policy, practice and quality improvement.

www.childbirthconnection.org/ebmc

## *Evidence-Based Maternity Care*

Overused practices in U.S. hospital-based maternity care include:

- labor induction
- epidural analgesia
- cesarean section
- continuous EFM
- rupturing membranes
- episiotomy

*Sakala C and Corry MP. Evidence-Based Maternity Care: What It Is and What It Can Achieve. 2008. Available at: http://transform.childbirthconnection.org/resources/datacenter/*



## *Evidence-Based Maternity Care*

Underused practices in U.S. hospital-based maternity care include:

- family practice maternity care, midwifery care
- smoking cessation interventions for pregnant women
- external cephalic version for breech presentation fetuses
- vaginal birth after cesarean
- continuous labor support
- measures for comfort, pain, relief, and labor progress

*Sakala C and Corry MP. Evidence-Based Maternity Care: What It Is and What It Can Achieve. 2008. Available at: http://transform.childbirthconnection.org/resources/datacenter/*

## *Evidence-Based Maternity Care*

Underused practices in U.S. hospital-based maternity care (continued):

- non-supine positions for giving birth
- delayed cord clamping in term and preterm babies
- early skin-to-skin contact
- breastfeeding and interventions to support initiation, duration
- practices to foster women's satisfaction with childbirth experience
- interventions for postpartum depression

*Sakala C and Corry MP. Evidence-Based Maternity Care: What It Is and What It Can Achieve. 2008. Available at: http://transform.childbirthconnection.org/resources/datacenter/*

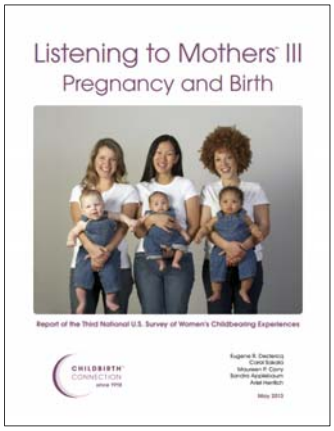


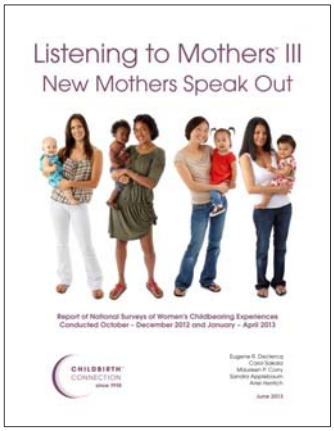
## Guidance for Safe, Effective Maternity Care

Without doubt, we need more knowledge to fill in gaps and evaluate changing maternity practices.

However, the large, growing body of systematic reviews can provide much valuable guidance for safe, effective maternity care practice.

# *Listening to Mothers III National Surveys: Pregnancy and Birth and New Mothers Speak Out*

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# *Listening to Mothers III National Surveys: Pregnancy and Birth and New Mothers Speak Out*

- Nationally representative data from initial survey of 2400 women who had given birth to a single baby in U.S. hospitals from July 2011 through June 2012 and could participate in English, and a follow-up survey of 1072 of the initial participants carried out several months later
- Surveys conducted by Harris Interactive, funded by the W.K. Kellogg Foundation, and guided by a National Advisory Council
- Data adjusted to reflect target population and propensity to be online
- Learn more and access the full initial and follow-up survey reports and related resources at http://bit.ly/LTM-III

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# Mothers' Attitude About Interfering with Birth Process

How much do you agree or disagree with the following statement? Giving birth is a process that should not be interfered with unless medically necessary. Do you…?

| | First-time mothers *n=977* | Experienced mothers *n=1423* | All mothers *n=2400* |
|---|---|---|---|
| Disagree strongly | 5% | 7% | 6% |
| Disagree somewhat | 11% | 8% | 10% |
| Neither agree nor disagree | 27% | 25% | 26% |
| Agree somewhat | 25% | 25% | 25% |
| Agree strongly | 32% | 35% | 34% |



# Mothers' Attitudes Toward Maternity-Related Tests and Treatments

| Base: all follow-up *LTM III* mothers *n=1072* | Strongly agree | Agree | Not sure | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| Newer maternity tests and treatments are generally improvements over older ones | 29% | 45% | 15% | 9% | 1% |
| Women can be confident that care recommendations from maternity care providers are based on up-to-date medical evidence about what works best | 28% | 54% | 8% | 8% | 2% |
| In general, getting more maternity tests and treatments is better quality care than getting fewer tests and treatments | 23% | 40% | 15% | 18% | 4% |
| Maternity tests and treatments that work the best usually cost more than those that don't work as well | 22% | 30% | 22% | 23% | 4% |
| Too many women do not get the maternity tests and treatments they need | 20% | 40% | 16% | 18% | 5% |
| Too many women get maternity tests and treatments that they don't really need | 14% | 29% | 18% | 29% | 11% |

# Maternity Care Practices: Information and Choice

**How much do you agree or disagree with each of the following statements about your options for maternity care tests treatments, or procedures?**

| Base: all follow-up *LTM III* mothers *n=1072* | Strongly agree | Agree | Disagree | Strongly disagree |
|---|---|---|---|---|
| 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 | 36% | 55% | 7% | 2% |
| In deciding about care, I would like my maternity care provider to always discuss the option of choosing no test or treatment | 26% | 62% | 9% | 2% |
| I would like my maternity care provider to help me understand how much each option will cost me and my family | 25% | 61% | 9% | 6% |
| I prefer to rely on my maternity care provider to make the best decisions for me | 14% | 51% | 28% | 7% |



# Mothers' Ratings of U.S. Maternity Care and Health Care Quality

| | Maternity care in the United States Base: all initial *LTM III* mothers *n=2400* | Health care in the United States Base: all follow-up *LTM III* mothers *n=1072* |
|---|---|---|
| Excellent | 36% | 19% |
| Good | 49% | 43% |
| Fair | 14% | 33% |
| Poor | 2% | 5% |

$p < .01$ for differences between maternity care and health care generally

# Rates of intervention that mothers experienced around the time of birth

| Intervention | Rate among all mothers |
|---|---|
| **Labor induction** | |
| Attempted self-induction | 29% |
| Self-induced labor* | 13%** |
| Attempted medical induction | 41% |
| Medically induced labor | 30% |
| Total attempted induction | 53% |
| **Synthetic oxytocin ("Pitocin"** | |
| To induce labor | 26% |
| To speed up established labor | 31% |
| To induce and/or speed up labor | 50% |
| **Breaking of membranes** | |
| To induce labor | 16% |
| To speed up established labor | 20% |
| To induce and/or speed up labor | 36% |

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*Base: all follow-up LTM III mothers *n=1072*
**Most who reported that self-induction brought on labor also had medical induction



# Rates of intervention that mothers experienced around the time of birth

| Intervention | Rate among all mothers |
|---|---|
| **Electronic fetal monitoring** (among mothers who experienced labor) | |
| Continuously or for most of labor* | 66% |
| Intermittently or as a baseline measure* | 23% |
| Any electronic fetal monitoring* | 89% |
| **Pain medications** | |
| Epidural analgesia | 67% |
| Narcotics | 16% |
| General anesthesia | 7% |
| Use of any pain medication | 83% |
| **Assisted vaginal birth** | |
| Vacuum extraction | 7% (10%)** |
| Forceps | 4% (6%)** |
| Vacuum extraction or forceps | 11% (15%)** |

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*Base: all follow-up LTM III mothers *n=1072*
**Figures in parentheses are rates among vaginal births

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# Rates of intervention that mothers experienced around the time of birth

| Intervention | Rate among all mothers |
|---|---|
| **Other pushing phase interventions** | |
| Directed pushing* | 47% (71%)** |
| External pressure on belly to move baby down* | 18% (28%)** |
| Episiotomy | 12% (17%)** |
| Back-lying position for pushing out baby | 47% (68%)** |
| **Cesarean section** | |
| Initial ("primary") | 15% |
| Repeat cesarean | 16% |
| Initial and repeat cesarean | 31% |
| **Other interventions** | |
| Intravenous drip | 62% |
| One or more vaginal exams | 51% |
| Bladder catheter | 47% |
| Initial separation of baby for routine care | 26% |

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*Base: all follow-up LTM III mothers *n=1072*
**Figures in parentheses are rates among vaginal births

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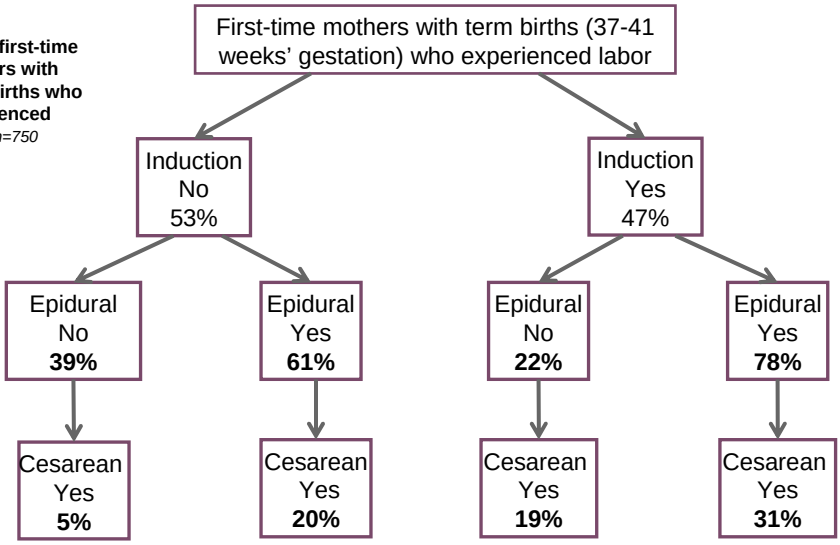
"I didn't like being strapped down, forbidden to move around, and not given any food."

- ***Listening to Mothers*℠*III: New Mothers Speak Out***
survey participant

**read the full report at**: http://bit.ly/LTM-III
twitter**: #LTM3**

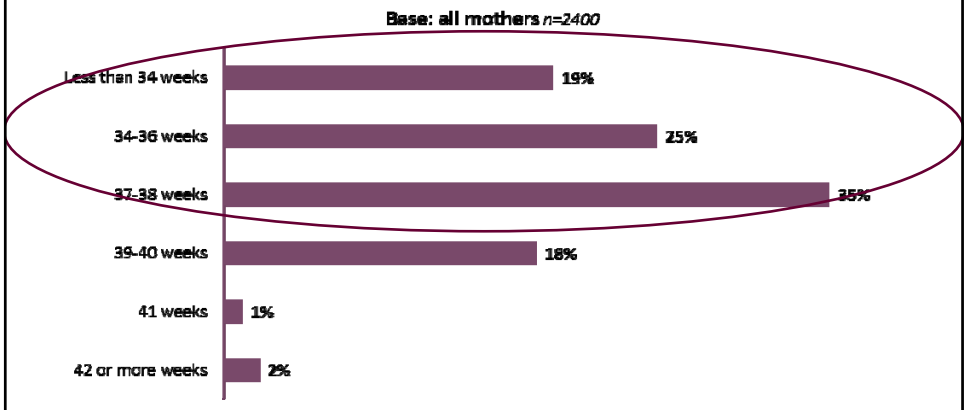
# Cascade of intervention in first-time mothers with term births who experienced labor

**Base: first-time mothers with term births who experienced labor** *n=750*




In this group, which included 85% of first-time mothers, the overall epidural rate was 69% and overall cesarean rate was 21%.

# Mothers' Identification of Earliest Week in Pregnancy When It Is Safe to Deliver a Baby Absent Complications Requiring Earlier Delivery



# Mothers' Knowledge of Labor Induction Complications

How much do you agree or disagree with each of the following statements concerning medical induction of labor, that is, using drugs or other methods to try to cause labor to begin?

| | **If a baby appears to be large at the end of pregnancy, it makes sense to induce labor** *n=1200* | **Labor induction lowers the chance that a woman will give birth by cesarean** *n=1200* |
|---|---|---|
| Agree strongly | 24% | 11% |
| Agree somewhat | 32% | 21% |
| Disagree somewhat | 17% | 24% |
| Disagree strongly | 12% | 18% |
| Not sure | 15% | 26% |



# Mothers' Knowledge of Cesarean Section Complications

A cesarean section…

| | **Increases the chance of serious problems with the placenta in any future pregnancies** *n=1200* | **Lowers the chance that a baby will have breathing problems at the time of birth** *n=1200* |
|---|---|---|
| Disagree strongly | 8% | 14% |
| Disagree somewhat | 15% | 18% |
| Not sure | 38% | 37% |
| Agree somewhat | 24% | 18% |
| Agree strongly | 15% | 12% |

## Mothers' Experience of Pressure from a Provider to Have Three Interventions by Whether Intervention was Experienced

| Intervention | Experience of pressure among mothers who did not have intervention* | Experience of pressure among mothers who had intervention | Experience of pressure among all mothers |
|---|---|---|---|
| Labor induction | 8% | 25% | 15% |
| Epidural analgesia | 19% | 13% | 15% |
| Cesarean section | 8% | 25% | 13% |
| Primary cesarean | 7% | 28% | 11% |
| Repeat cesarean | 28%** | 22% | 23% |

* $p < .01$ for all comparisons between those having and not having the intervention
** Mothers having a VBAC

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"I think caregivers are too quick to induce labor once a mother hits 39 weeks because it is more convenient for them. I think they are more concerned with their schedule than the health and well being of the mother and baby."

- ***Listening to Mothers III*** survey participant

**read the full report at**: http://bit.ly/LTM-III
twitter**: #LTM3**

# Mothers' Experiences Making Three Labor and Birth Decisions

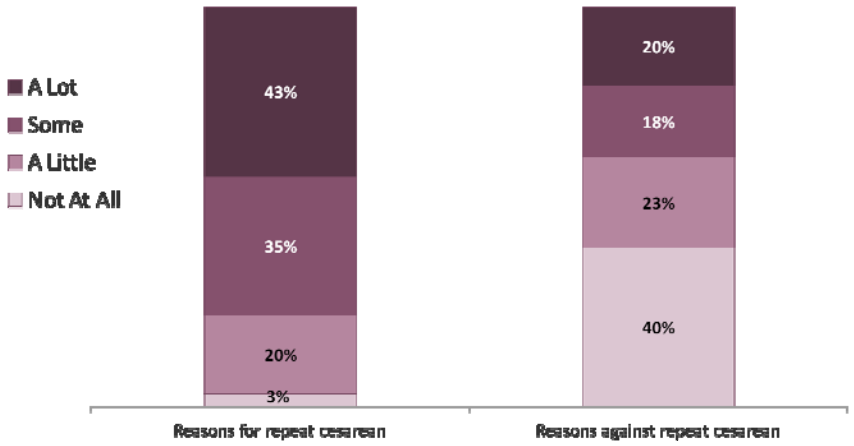
- Three questions explored whether decision making reflected standards for shared decision making.
- Two involved situation where a mother without prior cesarean was told that her baby might be getting quite large, which might have involved discussion with care provider on labor induction or scheduled cesarean, while the third examined decision making after one or two prior cesareans.
- Best current evidence does not support these interventions when a fetus "might" be large and does support offering VBAC to nearly all women with one or two prior cesareans



# Shared Decision Making after Cesarean

| **Base: had had 1-2 c-sections and provider mentioned having repeat c-section** | |
|---|---|
| Talked with maternity care provider about the reasons to schedule another cesarean "some" or " a lot" | 77% |
| Talked with maternity care provider about the reasons *not to* schedule another cesarean "some" or " a lot" | 38% |
| Maternity care provider explained that there were choices in how to give birth after a previous cesarean | 73% |
| Talked with maternity care provider about the option of planning a vaginal birth after cesarean (VBAC) "some" or "a lot" | 38% |
| Maternity care provider expressed an opinion about whether or not to schedule another cesarean | 72% |
| Maternity care provider thought mother should schedule another cesarean (among those who expressed opinion) | 88% |
| Maternity care provider asked whether or not mother wanted to schedule another cesarean | 76% |
| Made the final decision whether or not to schedule another cesarean (% mother's decision/% provider's/% shared decision) | 40/21/39 |
| Knowing then what you know now, would definitely make the same decision about whether or not to schedule another cesarean | 63% |
| Percent of mothers in series who gave birth by repeat cesarean | 93% |

## How Much Provider Talked About Reasons to Have and Not to Have Repeat C-Section




Base: had 1 or 2 prior cesareans and provider mentioned possibility of having a repeat cesarean *n=322*

*See: Fowler et al. How patient centered are medical decisions. JAMA Intern Med 2013:1215-*



"I would have liked more information about cesareans as this ruins my plans or makes it harder to have a big family."

- ***Listening to Mothers III*** survey participant

**read the full report at**: http://bit.ly/LTM-III

twitter**: #LTM3**

## Mothers' experience of selected new-onset health problems in first two months and at six months or more after birth

| Base: all mothers eligible for question (see notes) | In first two months | | | Problem persisted to six months or more |
|---|---|---|---|---|
| | Major new problem | Minor new problem | Major/minor new problem | |
| **Vaginal only*** | | | | |
| Painful perineum *n=1656* | 11% | 30% | 41% | 7% |
| Infection from cut or torn perineum *n=1656* | 5% | 13% | 18% | 4% |
| **Cesarean only** (base varies) | | | | |
| Pain at site of cesarean incision *n=744** | 19% | 39% | 58% | 16% |
| Itching at cesarean incision *n=351*** | 13% | 38% | 51% | 20% |
| Numbness at cesarean incision site *n=351*** | 12% | 36% | 48% | 20% |
| Infection at site of cesarean incision *n=744** | 8% | 16% | 24% | 5% |
| **All mothers** *n=2400** | | | | |
| Urinary problems | 9% | 22% | 31% | 11% |
| Bowel problems | 9% | 21% | 30% | 9% |

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*Base: initial *LTM III* mothers with a vaginal birth (*n=1656*), a cesarean birth (*n=744*), or either (*n=2400*).
**Base: follow-up *LTM III* mothers with a cesarean birth (*n=351*) or with either a vaginal or cesarean birth (*n=1072*)



## Mothers' experience of selected new-onset health problems in first two months and at six months or more after birth

| Base: all mothers eligible for question (see notes) | In first two months | | | Problem persisted to six months or more |
|---|---|---|---|---|
| | Major new problem | Minor new problem | Major/minor new problem | |
| **All mothers n=1072*** | | | | |
| Sleep loss | 21% | 38% | 58% | 30% |
| Feeling stressed | 17% | 37% | 54% | 34% |
| Physical exhaustion | 16% | 35% | 51% | 27% |
| Weight control | 16% | 28% | 45% | 29% |
| Other breastfeeding problem | 16% | 17% | 33% | 5% |
| Lack of sexual desire | 13% | 30% | 43% | 24% |
| Sore nipples/breast tenderness | 12% | 35% | 48% | 9% |
| Backache | 12% | 34% | 46% | 26% |
| Feelings of depression | 10% | 21% | 31% | 15% |
| Heavy bleeding | 9% | 18% | 27% | 8% |
| Frequent headaches | 8% | 21% | 29% | 19% |
| Painful intercourse | 7% | 20% | 27% | 10% |
| Hemorrhoids | 6% | 17% | 23% | 9% |
| Breast infection | 6% | 9% | 15% | 3% |

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*Base: initial *LTM III* mothers with a vaginal birth (*n=1656*), a cesarean birth (*n=744*), or either (*n=2400*).

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## Conclusions:
## Concern About Overuse of Maternity Care Practices Not Supported by Best Evidence or Best Practice

- High rate of adjusting due date at end of pregnancy (mostly moving it forward); large proportion of labor induction for non-medical reasons; considerable caregiver support for labor induction and cesarean for suspected big baby
- Failing to present VBAC as an option for many women with one or two prior cesareans; considerable proportion of care providers and hospitals unwilling to offer VBAC
- Considerable experience of caregiver pressure to have induction, cesarean, epidural; most moms with episiotomy did not have a say in it



## Conclusions:
## Concern About Overuse of Maternity Care Practices Not Supported by Best Evidence or Best Practice

- More than six in ten women had two or more among five consequential intrapartum interventions; evidence of “cascade of intervention” with one apparently increasing likelihood of others; 2/3 of women with vaginal birth gave birth lying on their backs
- One baby in four primarily with hospital staff for routine care in first hour after birth; more than 2 babies in 5 were not “skin-to-skin” with mothers just after birth
- Many mothers experienced ill-advised hospital practices that undermine breastfeeding

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## Conclusions: Concerns About Women's Readiness to Participate in Their Care

- A majority could not correctly identify two labor induction facts and two adverse effects of cesarean section; a majority identified unsafe gestational ages as safest time to deliver a baby, absent complications
- Despite quality concerns noted above, 47% rated maternity care providers as "completely trustworthy" and additional 33% as "very trustworthy"
- Despite quality concerns noted above, 36% rated quality of maternity care in U.S. as excellent and 47% as good.



## *Listening to Mothers* Surveys: Guideposts to Help Accelerate Improvement

- Close gaps between actual and more optimal experiences through policy, practice, comparative effectiveness research, and education
- Expand performance measurement, reporting, and transparency, and quality improvement programs
- Enhance ability of maternity care system to protect, promote, and support physiologic childbirth for this largely healthy population of women and their fetuses/newborns

## *Listening to Mothers III* Surveys: Guideposts to Help Accelerate Improvement

- Engage and activate childbearing women to become informed, understand their rights, and make wise decisions
- Women need access to skills and tools to take these steps forward, including knowledge about quality maternity care, high-quality decision aids and shared decision making, critical appraisal skills, and help in navigating the maternity care system



## CER Needed to Fill Knowledge Gaps

Outcomes of interest to women and families include

- quality of life
- physical and emotional functioning, recovery
- breastfeeding
- adaptation to parenthood and family functioning
- new-onset maternal morbidity
- payer and out-of-pocket cost of intrapartum care

Give attention to optimal outcomes (e.g., spontaneous vaginal birth, exclusive breastfeeding) and harms

## CER Needed to Fill Knowledge Gaps

Need better understanding of potential unintended impact (harms) of intrapartum care processes, including

- effects of unneeded interventions
- disruption of hormone systems, short- and longer-term
- perinatal origins of disease; impact on immune, metabolic, and other systems
- new-onset maternal morbidity
- child morbidity
- mortality



## CER Needed to Fill Knowledge Gaps

Research Follow-up to at Least 1 Year

Just 16% of most influential RCTs of intrapartum care measured any newborn outcomes after hospital discharge

We know little about how different birth settings compare with respect to longer-term effects, e.g.,

- maternal morbidity, including mental health, pelvic floor outcomes
- child morbidity, including childhood infectious and chronic diseases
- family functioning and relationships
- breastfeeding

*Teune MJ et al. Long-term child follow-up after large obstetric randomised controlled trials for the evaluation of perinatal interventions: a systematic review of the literature. BJOG 2013;120(1):15-22.*

## Fill Gaps in Knowledge About Women's Experience of Care

CAHPS generic Hospital, Clinician, and Health Plan surveys are poorly suited to maternity care

Maternity CAHPS surveys are needed to measure

- experience of intrapartum care across the various settings and types of care providers
- diverse dimensions of pain (versus whether pain is "controlled")
- newborn care (hospital survey for single patient; many questions on child survey do not apply to newborns)
- shared decision making, informed choice and autonomy
- care coordination and care transitions
- relevant episode of care (versus "last 12 months")

CAHPS: Consumer Assessment of Healthcare Providers and Systems
https://www.cahps.ahrq.gov



## First National Maternity Care Shared Decision Making Initiative

- Informed Medical Decisions Foundation and Childbirth Connection engaged in partnership to foster maternity care shared decision making

pregnantMe
a smart decision guide

# Thank You!


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