

Informed or Misinformed Consent? Abortion Policy in the United States

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Abstract Since 2010, the United States has witnessed a dramatic expansion of state-based restrictions on abortion. The most common of these are informed consent statutes, which require that a woman seeking an abortion receive a state-authored informational packet before the abortion procedure can be performed. These laws, in addition to requiring the provision of information about alternatives to and risks of abortion, all also require details of embryological and fetal development. This article presents the findings of a comprehensive study of state informed consent materials regarding embryological and fetal development. To conduct this study, we recruited a panel of experts in human anatomy to assess the accuracy of these materials in the context of the constitutional standard established in *Planned Parenthood of Southeastern Pennsylvania et al. v. Robert P. Casey et al.* (505 U.S. 833 (1992)): that such information must be “truthful” and “nonmisleading.” We find that nearly one-third of the informed consent information is medically inaccurate, that inaccurate information is concentrated primarily in the earlier weeks of pregnancy and is clustered around particular body systems. We discuss the implications of our findings for the question of the constitutionality of informed consent laws as they have been implemented in practice.

Keywords abortion, women’s reproductive health, reproductive politics, fetal, embryological

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Since 2010, the United States has witnessed a dramatic expansion of state-based restrictions on abortion. The most common of these are informed consent statutes, which require that a woman seeking an abortion receive a state-authored informational packet before the abortion procedure can be performed. These laws, often labeled “Woman’s Right to Know” acts, typically require details of fetal development and information about alternatives to abortions and risks associated with abortion and pregnancy. The impact of these laws is potentially great: 66 percent of all women seeking abortions live in informed consent states.¹ Yet there has been little systematic analysis of the accuracy of materials that states mandate that women view.²

This article presents the findings of a comprehensive study of state informed consent materials, with a particular focus on information regarding embryological and fetal development. First, we discuss the constitutional standard for informed consent laws as set out in the US Supreme Court’s decision in *Planned Parenthood of Southeastern Pennsylvania et al. v. Robert P. Casey et al.* (505 U.S. 833 (1992)). Second, we provide an overview of detailed provisions of informed consent laws in force in the states in 2013. Third, we present the methods we used for collecting and assessing informed consent materials from these states. Since the bulk of the material provided to women focused on embryological and fetal development, we concentrated our analysis on this information, and we recruited a team of human anatomy specialists to assist us in evaluating this information for medical accuracy. Fourth, we present the primary findings of this evaluation, and we discuss the implications of our findings for the constitutionality of informed consent laws and whether these laws meet the US Supreme Court’s standard that the information be “truthful” and “nonmisleading.”

In *Casey* (505 U.S. at 916), the US Supreme Court affirmed three principles central to the constitutionality of informed consent laws: that the state has an interest in fetal life from the moment of conception, that the state could prefer childbirth over abortion, and that the state could enact regulations to ensure that a woman’s choice was “thoughtful and

1. To determine this percentage, we used 2011 Guttmacher Institute data to calculate the total number of abortions that occurred in the thirty-five states with informed statutes in effect ($n = 694,920$) and divided this number by the total number of abortions that occurred in the United States: $(1,058,490) = 694,920/1,058,490 = 65.6\% \approx 66\%$.

2. The most recent study was conducted by the Guttmacher Institute in 2006 and focused on information regarding associations between breast cancer and abortion, fetal pain information, psychological effects of abortion, and referrals to counseling centers, such as “crisis pregnancy centers” (Richardson and Nash 2006).

informed.” These principles, the court argued, were consistent with both a woman’s right to reproductive choice and doctor-patient medical privacy.

First, the court found that the state had an “*important and legitimate interest in potential life*” (*Casey*, 505 U.S. at 871 (emphasis added)). The state’s interest in “protecting the life of the unborn,” *Casey* argued, was established “from the outset of the pregnancy” and “throughout pregnancy” (505 U.S. at 873, 932, 876).³ The court held that this interest in fetal life, even before viability, was entirely consistent with *Roe v. Wade*: “That portion of the decision in *Roe* has been given too little acknowledgment and implementation by the Court in its subsequent cases” (*Casey*, 505 U.S. at 871). Given the state’s interest in “potential life,” states retained the power to provide to a woman information that had “no direct relation to her health” but was relevant only to “the effect on the fetus” (*Casey*, 505 U.S. at 915, 863, 883). Informed consent materials, the court held, “need not be defined in such narrow terms that all considerations of the effect on the fetus are made irrelevant” (*Casey*, 505 U.S. at 883). The state’s interest in fetal life was the foundation for claiming that the state could mandate certain regulations of the abortion procedure, including the provision of information about the fetus to the woman prior to an abortion. As the court stated: “The very notion that the State has a substantial interest in potential life leads to the conclusion that not all regulations must be deemed unwarranted” (*Casey*, 505 U.S. at 876). The “inevitable consequence” of the state interest in “protecting the life of the unborn,” the court argued, meant that “states are free to enact laws to provide a reasonable framework for a woman to make a decision that has such profound and lasting meaning” (*Casey*, 505 U.S. at 873, 873, 916).

Second, in providing information to a pregnant woman, the state could *prefer childbirth over abortion*. The court found that there was a long legal history of the state’s right to express this preference, as affirmed in both the *Webster v. Reproductive Health Services* and *Poelker v. Doe* decisions: “The Constitution does not forbid a State or city, pursuant to democratic processes, from expressing a preference for normal childbirth” (*Webster*, 492 U.S., at 511 (opinion of [505 U.S. 833, 873], the court quoting *Poelker*, 432 U.S. 519, 521 (1977)). The provision of “information relating to fetal development,” the court held, “might cause the woman to choose childbirth over abortion” and thereby was a reasonable use of state power (*Casey*, 505 U.S. at 883). This stands in contrast to the court’s previous

3. As the court put it, regarding *Roe*: “Yet it must be remembered that *Roe v. Wade* speaks with clarity in establishing not only the woman’s liberty but also the State’s ‘important and legitimate interest in potential life’” (*Roe*, *supra*, at 163).

ruling in the 1983 *Akron v. Akron Center for Reproductive Health, Inc.* decision, where the court had held as unconstitutional an Ohio law that mandated that a woman be given “information designed to dissuade the woman from having an abortion” and that a state impose “a rigid requirement that a specific body of information be given in all cases, irrespective of the particular needs of the patient” (476 U.S. 416, 103 S. Ct. 2481 (1983), 762).⁴

In *Casey*, the court argued that neither of these—neither the state’s attempts to dissuade a woman from an abortion nor the state’s mandate that a specific body of information be given to a woman—invalidated a state’s informed consent law. As the *Casey* decision stated: “Measures designed to advance this interest should not be invalidated if their purpose is to persuade the woman to choose childbirth over abortion” (505 U.S. at 878). As the court held: “Even in the earliest stages of pregnancy, the State may enact rules and regulations designed to encourage her to know that there are philosophic and social arguments of great weight that can be brought to bear in favor of continuing the pregnancy to full term” (*Casey*, 505 U.S. at 873).

Materials [shall be] designed to inform the woman of the probable anatomical and physiological characteristics of the unborn child at two-week gestational increments from fertilization to full term, including pictures representing the development of unborn children at two-week gestational increments, and any relevant information on the possibility of the unborn child’s survival; provided that any such pictures or drawings must contain the dimensions of the fetus and must be realistic and appropriate for the woman’s stage of pregnancy. The materials shall be objective, non-judgmental and designed [505 U.S. 833, 908] to convey only accurate scientific information about the unborn child at the various gestational ages. (Appendix to opinion of O’Connor, Kennedy, and Souter, JJ; Selected Provisions of the 1988 and 1989 Amendments to the Pennsylvania Abortion Control Act of 1982, 18 Pa. Cons. Stat. (1990))

Third, the court argued that the state could enact regulations meant to ensure that a woman’s choice was “*thoughtful and informed*” (*Casey*, 505 U.S. at 916; emphasis added). As the court held: “Requiring that the

4. In *Akron*, the Supreme Court had the opportunity to review multiple Ohio abortion regulations, one of which was informed consent. In fact, the seeds of *Casey* are sown in the dissent of *Akron*, where Justice Sandra Day O’Connor writes about the state’s interest in the potential life of the fetus and asserts that the “undue burden” test be applicable throughout pregnancy (*Akron*, 462 U.S. 416, 103 S. Ct. 2481 (O’Connor, J., dissenting)).

woman be informed of the availability of information relating to fetal development and the assistance available should she decide to carry the pregnancy to full term is a reasonable measure to ensure an informed choice" (*Casey*, 505 U.S. at 883). The court additionally held: "Most women considering an abortion would deem the impact on the fetus relevant, if not dispositive, to the decision. In attempting to ensure that a woman apprehend the full consequences of her decision, the State furthers the legitimate purpose of reducing the risk that a woman may elect an abortion, only to discover later, with devastating psychological consequences, that her decision was not fully informed" (*Casey*, 505 U.S. at 882). The court justified these laws on the grounds of women's purported ignorance of fetal development, the abortion procedure, or alternatives to abortion.⁵

Casey argued that informed consent laws did not violate the doctor/patient right to medical privacy: "Requiring that the woman be informed of the availability of information relating to the consequences to the fetus does not interfere with a constitutional right of privacy between a pregnant woman and her physician" (505 U.S. at 883). On this question of doctor-patient privacy, the court argued: "A requirement that a doctor give a woman certain information as part of obtaining her consent to an abortion is, for constitutional purposes, no different from a requirement that a doctor give certain specific information about any medical procedure" (*Casey*, 505 U.S. at 884). The court argued: "We see no constitutional infirmity in the requirement that the physician provide the information mandated by the State here" (*Casey*, 505 U.S. at 884).

In sum, the state could further its "legitimate interest in promoting the potential life of the unborn" by providing information to the woman to ensure that her decision was "thoughtful and informed" (*Casey*, 505 U.S. at 870, 872). This information could be biased in that it could "[express] a preference for childbirth over abortion" (*Casey*, 505 U.S. at 883). But this information must be "realistic" and "accurate scientific information." These provisions, the court held, violated neither the woman's constitutional right to choice nor the woman's right to medical privacy. As the court stated: "If the information the State requires to be made available to the woman is truthful and not misleading, the requirement may be permissible" (*Casey*, 505 U.S. at 882).

5. For instance, see the wording of the Pennsylvania statute that states that "reliable and convincing evidence has compelled the General Assembly to conclude and the General Assembly does hereby solemnly declare and find that . . . many women now seek or are encouraged to undergo abortions without full knowledge of the development of the unborn child or of alternatives to abortion" (18 Pa. Const. Stat. § 3202).

The *Casey* decision thus opened the door to the widespread passage of informed consent laws in the states. By 2013, thirty-seven states had abortion-related informed consent laws. (See appendix A for maps and lists of states.) Twenty-nine of these states specified that mandated scripts be delivered to any woman seeking an abortion. Most states followed the same general format in their mandates, including a list of alternatives to abortion (e.g., information about paternal liability and assistance from state and nonstate agencies), the medical risks of abortion and childbirth, and information regarding embryological and fetal development. By far, the bulk of the information provided to women focused on embryological and fetal development. We now turn to our evaluation of these materials.

Methodology

In 2013 we collected informed consent materials from the twenty-three states that had produced such materials and had made these materials publicly available.⁶ Typically, states required that printed and online informed consent materials include visual depictions and verbal descriptions of the “unborn” at two-week increments. States sometimes additionally specified that information on fetal development must include statements regarding the functionality of certain physical structures at various gestational ages, such as heart, brain, or lung development, or in the ability of a fetus to feel or experience pain.

Although we did not conduct a primary analysis of which agencies and authorities actually designed and produced the booklets, we were able to gather some information from the booklets themselves. In all cases, state health departments developed the informed consent brochures. Some states included an acknowledgments section in the informed consent booklet, citing some of the sources and contributions that influenced the production of the booklet. For example, Alaska and South Carolina write that a panel of medical experts appointed by state medical boards reviewed the information included in the booklets. States sometimes acknowledged that they had drawn information from the informed consent booklets of other states. States took information from Minnesota (Alaska, Georgia, Missouri, North Dakota); Texas (Alaska, Arizona, Oklahoma); Virginia (Arizona,

6. Of the thirty-seven states that had informed consent laws, twenty-nine required state-authored informed consent materials. These were different from the customary informed consent laws in eight states that codify the medical standard of informed consent but leave the content of that information to the discretion of the health care provider. Laws in two of the twenty-nine states, Massachusetts and Montana, were enjoined, and thus no informed consent materials were developed. Indiana had not yet developed its informed consent materials. Informed consent materials mandated by Wisconsin, Mississippi, and Kentucky were not made publicly available.

Minnesota, Virginia); Kansas (Georgia, Minnesota, Missouri); Louisiana (Georgia, Kansas, Minnesota); Nebraska (North Carolina); Ohio (North Carolina, Virginia); Utah (North Carolina); Pennsylvania (Virginia); South Dakota (Virginia); and Alaska (North Dakota).

The booklets included citations for illustrations by Peggy Gerrity (Arizona, Georgia, Minnesota, Nebraska, North Carolina, Virginia) and photographs by Lennart Nilsson (Georgia, Idaho, Kansas, Minnesota, Ohio, Oklahoma, Pennsylvania, Texas) and Robert Wolfe (Idaho, Ohio). Booklets also cited medical texts, including Keith L. Moore, T. V. N. Persaud, and Kohei Shiota's *Color Atlas of Clinical Embryology* (Kansas); Alexander Tsiaras and Barry Werth's *From Conception to Birth* (Kansas); Moore and Persaud's *The Developing Human* (South Carolina); Gary C. Schoenwolf et al.'s *Larsen's Human Embryology* (South Carolina); F. Gary Cunningham et al.'s *Williams Obstetrics* (South Carolina, Virginia); and Maureen Paul et al.'s *A Clinician's Guide to Medical and Surgical Abortion* (Virginia).

Several states cited the inclusion of information from external departments and organizations, including the Centers for Disease Control and Prevention (Arizona); the American Congress of Obstetrics and Gynecologists (Missouri, North Carolina, South Carolina); Animated Dissection of Anatomy for Medicine (A.D.A.M.) (Missouri); the Endowment for Human Development (North Carolina); and the Respect Life Office of the Roman Catholic Diocese of Charleston, South Carolina (South Carolina). The Virginia booklet gave the names of two physicians from the University of Virginia who reviewed the informed consent materials, and the North Dakota booklet acknowledged the contributions of a nurse.

During the spring of 2013, we collected all of the informed consent materials available from these states, primarily in portable document format (PDF) as booklets downloaded from the states' department of health or similar websites.⁷ We extracted all statements regarding embryological and fetal development from these brochures. After eliminating all exact duplicates, we identified a total of 954 individual statements in these packets. We then combined statements that were essentially similar in content. For instance, the following three statements, "The embryo is about ½ inch long (14 mm)," "Length from crown to rump ½ inches," and "The embryo is ½ to ¾ inches in length," were combined into a single statement reading, "The embryo is ½ to ¾ inches in length." In cases where two statements of fact were made in one sentence, we created survey items for each statement.

7. Some of the materials appear in website format only, such as in Michigan.

We aggregated 896 statements about fetal development into a Qualtrics survey instrument. To limit geographical bias from the assessment of accuracy, we removed all state identifying information for the purpose of the experts' review. We later added state identifying information back into our database to conduct our state-by-state analysis. To focus our review only on the medical accuracy of statements, we also eliminated all photos, drawings, and images. We organized the statements by two-week developmental periods (as they were presented in state materials) and standardized by age as weeks since "last menstrual period" (LMP). Statements were further subdivided by body part or function (e.g., as "nervous system," "size," or "eyes"). These subdivisions reflected the content of state-produced booklets, which often went into great detail about particular body parts or systems, such as the heart, brain, eyes, ears, lungs, nervous system, and extremities, like fingers and toes.

Following the standard set by the US Supreme Court in *Casey*, which mandates that informed consent materials must be "truthful" and "non-misleading," we created two 5-point evaluative scales. Our "truthfulness" scale contained possible scores ranging from 1 to 5, where 1 = "completely true"; 2 = "more true than false"; 3 = "equally true and false"; 4 = "more false than true"; 5 = "completely false"; and 6 = "unsure / don't know." We created equivalent categories for the nonmisleadingness scale (see fig. 1).

We recruited a team of seven specialists in embryological and fetal anatomy through the American Academy of Anatomists to evaluate these materials. Reviewers were not informed that the evaluation was related to abortion, but were given the following information:

A number of states provide patients at women's medical health facilities with information regarding embryonic and fetal development. This information varies from state to state. The survey we have developed contains a compilation of information from documents gathered from twenty-three states. We are asking your assistance in evaluating this information for medical accuracy.

Instructions to our experts included the following regarding our definitions of *medical accuracy*, *truthfulness*, and *nonmisleadingness*:

We are asking your assistance in evaluating this information for medical accuracy. By "medical accuracy" we mean information that is scientifically correct (in terms of biological development) AND information that is nonmisleading (meaning that it gives a "correct impression") to a patient seeking reproductive medical services. The survey presents

	true to false				non-misleading to misleading			
	completely true	more true than false	equally true and false	more false than true	completely false	more false than true	equally non-misleading and misleading	more misleading than non-misleading
	completely true	more true than false	equally true and false	more false than true	completely false	more false than true	equally non-misleading and misleading	more misleading than non-misleading
The embryo is too small to be seen	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At 4 weeks, the unborn child is less than 1/100th of an inch	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The embryo is less than 1/100th of an inch long	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The embryo is between 1/100 and 4/100 inch long at this time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The length is less than 1/8 inch	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The developing embryo is about the size of a pinhead	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The embryo is approximately .014 inches long which is the size of the thickness of a standard staple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Actual size= 1/100 of an inch long (.254 millimeters), about the size of a period at the end of a sentence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 1 Qualtrics Survey Example

statements of embryonic/fetal development in two-week segments (post-fertilization) and each segment is organized by body parts/systems. You will be asked to evaluate *each* statement separately according to *two* scales:

- First, rank the statement on the “truthfulness-falsity” scale;
- Second, rank the statement on the “nonmisleading-misleading” scale.

You may find that a statement is “technically true” but still “misleading” OR that a statement is “technically false” but “nonmisleading.” For example, the statement “The X organ is developing” may or may not be technically true, and may or may not mislead a patient about the general nature of embryonic development at that particular stage of development.

To make these assessments, we ask that you rely on your best professional judgment and/or you may consult scientific outside sources.

To reduce the burden on each expert, we divided our survey into two parts, one on early pregnancy (weeks 2–18) and one on late pregnancy (weeks 20–38), and randomly assigned experts to one of these surveys. Three experts reviewed statements on early pregnancy and four evaluated statements on late pregnancy. Of the seven experts, three were female and four were male. Of those who reported their age, two were over sixty and three were between fifty and sixty. They identified their professions as “college professor,” “researcher,” “embryologist,” or “medical college faculty.” Of the five who reported their years practicing in their field, their experience ranged from twenty-five to forty-five years. Six reported that they were practicing in the United States and one was practicing from Canada. In a brief, post-survey questionnaire, we asked reviewers about their political attitudes. Those four who reported their political leanings each identified as conservative, liberal, “somewhere in between,” or “other.” Of those who reported their religion, three reported that they were “atheists,” one reported Protestant “born-again or evangelical” Christian, and one reported “unsure / don’t know.”

In evaluating the scores of our reviewers, we collapsed the categories of the 5-point scales in a way that matches the constitutional standard in *Casey*: that information be both “truthful” and “nonmisleading.” To be counted as “medically accurate,” a statement had to have been rated as both truthful and nonmisleading by our reviewers. We calculated an average score on both the nonmisleading/misleading and true/false scales for each statement. In our analysis, we counted as “medically accurate” any

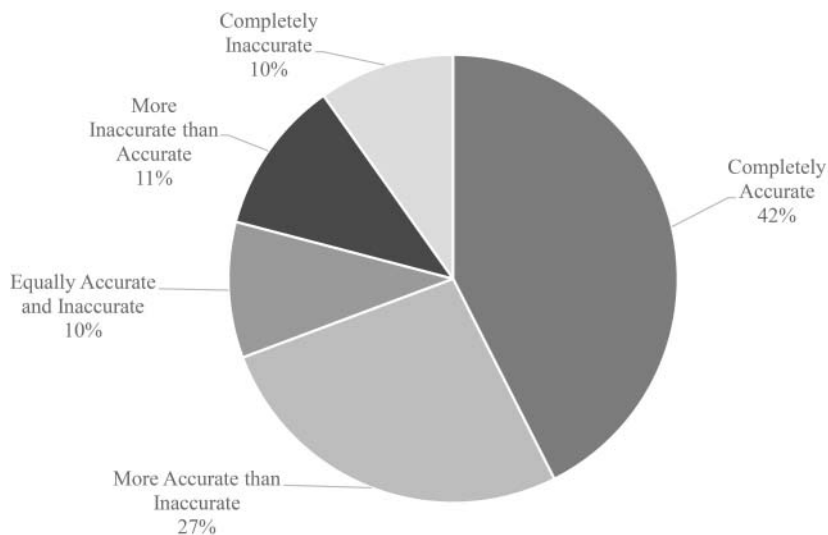


Figure 2 Percentages of “Medical Accuracy” for All Trimesters

statement that received an average score of less than 3 on either the truthfulness or misleadingness scale. Average values of 3 or more counted as “medically inaccurate.” Responses of “don’t know / unsure” did not affect a statement’s score. The following is our analysis of these results.

Findings

Finding 1: While most statements were medically accurate, about one-third of statements were rated as “medically inaccurate.” Of all statements, 69 percent were rated as “medically accurate”; 31 percent were rated as “medically inaccurate.” Figure 2 illustrates the percentage of total answers for each of our five scoring categories, for a summary of all medically in/accurate statements. Figures 3 and 4 illustrate the percentages of answers that were rated, respectively, as misleading/not misleading (fig. 3) or as true/false (fig. 4).

Examples of medical inaccuracies include the following: from week 2, “the head has formed” (average score of 5); from week 4, “brain activity can be recorded” (average score of 4.75); and from week 9, “hiccups begin” (average score of 4). By contrast, a statement rated as medically accurate regarding the same stage of brain development reads: “A ridge of tissue

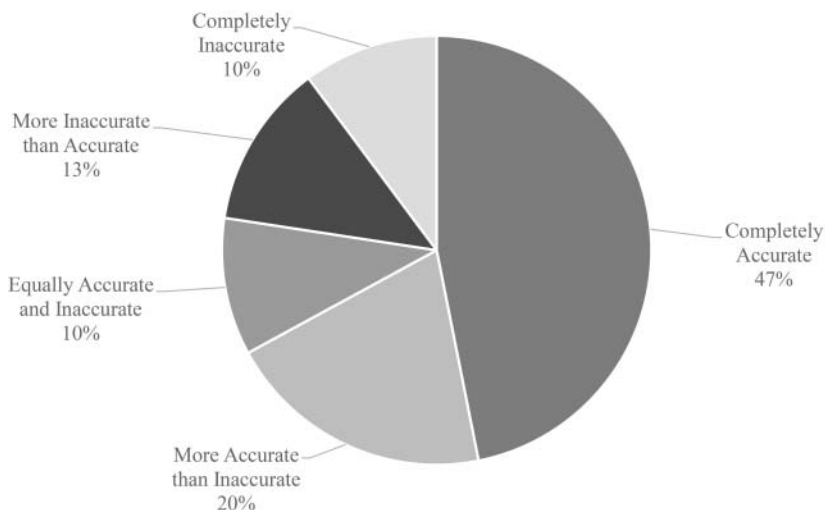


Figure 3 Percentages of Nonmisleading/Misleading for All Trimesters

forms down the length of the embryo. That tissue will later develop into the brain and spinal cord” (see appendixes B and C).

Overall, 29 percent of all responses received a rating of “don’t know / unsure.” We eliminated these responses from the analysis. One pattern we see is that the first and second trimesters had higher levels of “unsure” statements than the third trimester. If we look at statement content, we see that many of the statements rated as “unsure” pertained to traits not typically addressed in embryological medical texts, such as “activities” of the fetus (e.g., thumb sucking, right- and left-handedness, hands making a fist, complex facial expressions, fetal response to light touch, or fetal response to being “poked by a needle”), or they pertain to traits that vary widely between pregnancies, such as small variations in fetal weight and size.

We found no relationship between experts’ ratings of statements and either their demographic traits or attitudinal responses. After completing the survey, we asked each expert a range of attitudinal questions. These included questions regarding the relationship between religion and medical decision making by doctors, attitudes toward government regulation of medical procedures, general political views, and attitudes toward public health care provision. We also asked about attitudes toward abortion, including legality and restrictions on abortion (e.g., parental notification, public funding, waiting periods, and late-term abortion limits).

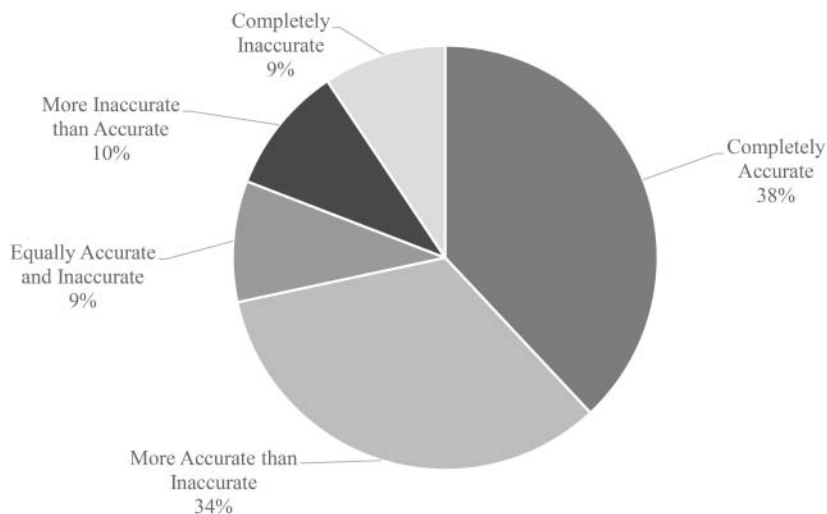


Figure 4 Percentages of True/False for All Trimesters

Region: The inaccuracies ranged from about 15 percent to 46 percent across states. Table 1 presents state rankings by percentages of inaccuracies. Included in this table are the percentages of statements rated as medically inaccurate (of all statements included in that state's informed consent materials related to embryological and fetal development); the total number of statements; and the number of inaccurate statements. For instance, of the twenty-three states, the state with the highest level of inaccuracies, North Carolina, presented seventy-eight factual statements in its state brochure, out of which thirty-six (or 46 percent) were rated as medically inaccurate. Alaska had the lowest level of inaccuracy, with 15 of its 102 statements (or 15 percent) rated as inaccurate.

In terms of a geographical relevance, we found a small, though not significant, association between region and levels of inaccuracy. Higher levels of inaccuracy were found in the South and Midwest, specifically the south Atlantic (23 percent), west south central (29 percent), and east north central (39 percent) regions. Figure 5 is a map that shows the various regions of states by level of inaccuracy.

Finding 2: "Medically inaccurate" statements were disproportionately concentrated in the first trimester of pregnancy and in the earliest weeks of the first trimester. A total of 45 percent of statements about the first trimester were rated as medically inaccurate (fig. 6) compared to 29

Table 1 State Rankings by Level of Medical Inaccuracy

State	Total <i>N</i> Statements	<i>N</i> of Incorrect Statements	Overall % Inaccurate
AK	102	15	14.71
WV	108	19	17.59
GA	122	22	18.03
AL	99	18	18.18
SC	131	26	19.85
ID	167	34	20.36
MN	132	27	20.45
VA	157	35	22.29
UT	69	16	23.19
LA	127	30	23.62
ND	127	30	23.62
SD	127	30	23.62
NE	101	24	23.76
PA	96	23	23.96
AR	96	23	23.96
MO	152	39	25.66
AZ	100	28	28.00
OH	46	13	28.26
OK	131	43	32.82
TX	119	41	34.45
KS	106	46	43.40
MI	88	39	44.32
NC	78	36	46.15
Total	2,581	657	25.46
Common (Consolidated) Statements	896	278	31%

percent in the second trimester (fig. 7) and 13 percent in the third trimester (fig. 8). We see, therefore, a pattern of proportionally decreasing percentages of medical inaccuracy as pregnancy progresses.

Relatedly, “medically inaccurate” statements were also concentrated in the earliest weeks of pregnancy, as illustrated by figure 9.

Reviewers found “medically inaccurate” information disproportionately concentrated in weeks 2–6 (LMP) of pregnancy, with over 50 percent of statements in week 2 found to be inaccurate, over 30 percent of statements in week 4 and 38 percent of statements in week 6 “medically inaccurate.” Rates of inaccuracy also increased between weeks 8 and 16 and rose to over 20 percent in week 26.

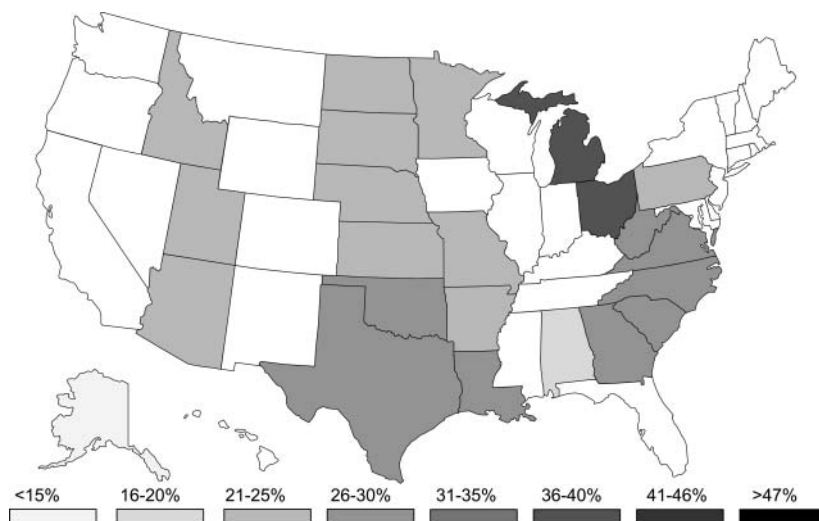


Figure 5 Inaccuracies by State—Division/Region

Of all the statements, a small number, 169 (9 percent), were rated unanimously as both true and nonmisleading by all of the experts who reviewed those statements. These statements were concentrated more heavily in the third trimester.

Finding 3: “Medically inaccurate” statements were disproportionately concentrated on particular body parts / systems / functions. Although the term *unborn baby* is technically not medically accurate, experts were just slightly more likely to rate as medically inaccurate statements that contained the term *unborn* (35 percent) or *baby* (23 percent) as opposed to *fetus* (21 percent). Reviewers were not, apparently, just ruling statements as inaccurate, out of hand, for using the term *unborn baby*.

Overall, experts found particular patterns of inaccuracies: fetal development was “accelerated” by misrepresenting development of certain body systems earlier than in developmental reality. And body systems that appear to attribute human “intentionality” or more “baby-like” characteristics to the embryo or fetus, such as breathing, seeing, crying, or experiencing pain, were more likely to be misrepresented at earlier stages of development.

Medical inaccuracies were grouped around statements about certain body systems, particularly extremities, internal development, and size and weight, as well as statements about viability and activity. Statements about extremities were found to have the highest level of inaccuracy (29.94

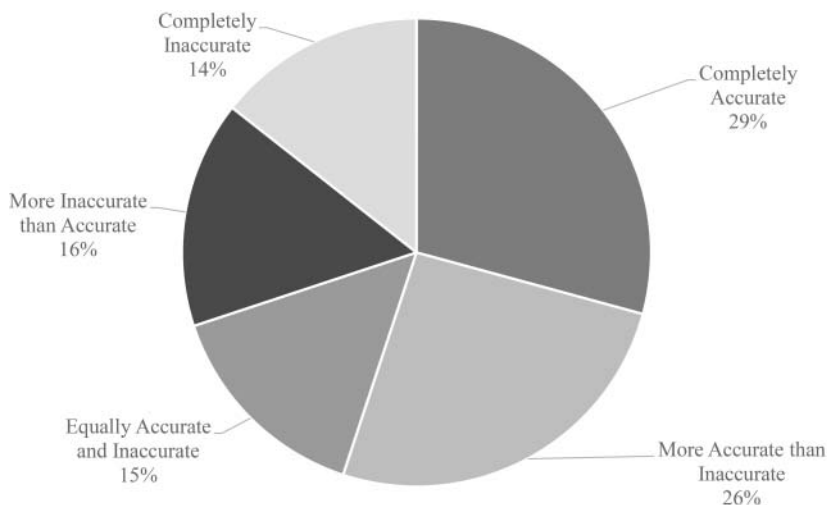


Figure 6 First Trimester Percentages of “Medical Accuracy”

percent). Statements about limbs, fingers and toes, and nails were included in this category. For example, “arm and leg buds are present” at week 2 LMP was unanimously rated 5, or completely inaccurate. Additionally, “fingers, toes, ankles, and wrists are completely formed” at week 6 LMP was also rated as completely medically inaccurate.

More than one-quarter (26.13 percent) of statements about internal development were also inaccurate. This category includes the development of organs such as the heart, liver, lungs, and kidneys, as well as development of skeletal and nervous systems. For example, “the stomach and intestines are forming” at week 2 LMP was rated 4.3 by reviewers, as medically inaccurate. Similarly, statements about brain and nervous system development were found to be inaccurate. At week 4 LMP, “the brain develops into five areas and some cranial nerves are visible” was rated as medically inaccurate (4.6) by reviewers. Statements about bones were found to be inaccurate as well; for example, reviewers rated “bones become solid” at week 12 LMP a 4.5.

Size and weight categories also contained many statements that were inaccurate (26.89 percent), with most of the discrepancies in the second and third trimesters. Size and weight inaccuracies tended to represent the size of the fetus as larger than is medically accurate.

Statements about activity or movement of the fetus were also found to be inaccurate—about 23.15 percent of all statements. This category included

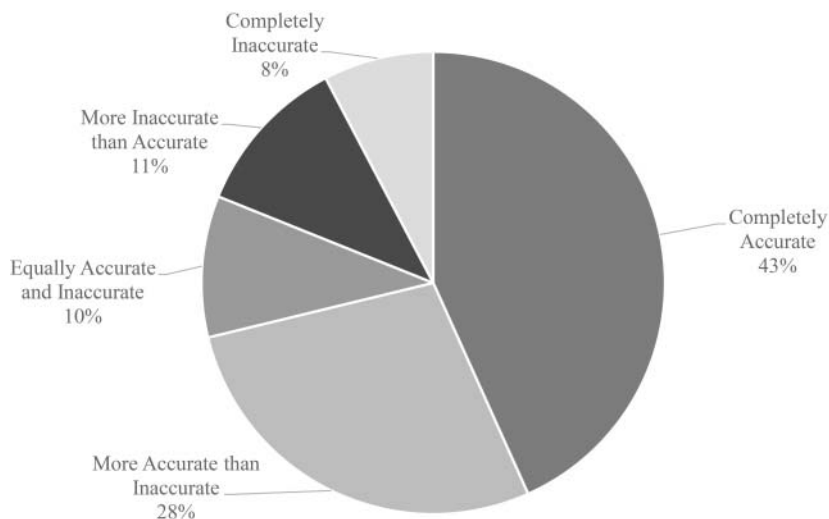


Figure 7 Second Trimester Percentages of “Medical Accuracy”

statements that focused on fetal movement or action, some of it attributed to fetal intention. For example, “the vocal chords are active and the fetus can cry” was rated completely inaccurate (5) for week 16 LMP. “The fetus can now blink” at week 16 LMP was similarly rated completely inaccurate (5). Also, “by nine weeks, hiccups begin” at week 6 LMP was rated as mostly inaccurate (4).

Of viability statements, particularly those in the second trimester, 20.53 percent were found to be inaccurate. For example, “[the fetus has a] 21 percent chance of survival with appropriate high-risk newborn care” (from week 20) rated an average score of 4.75. These statements were also notable in their variance. Compare a statement rated as medically inaccurate that claimed that there was an 81 percent survival rate in week 24 LMP with another statement on viability from week 20 rated as medically accurate that maintained that “survival outside the uterus at this stage is not yet possible.”

Implications of Findings

We now turn to a reassessment of the principles laid out in *Casey*: that the state can express an interest in fetal life from the moment of conception, that the state can prefer childbirth over abortion in its provision of information, and that the state can enact regulations to ensure that a woman’s

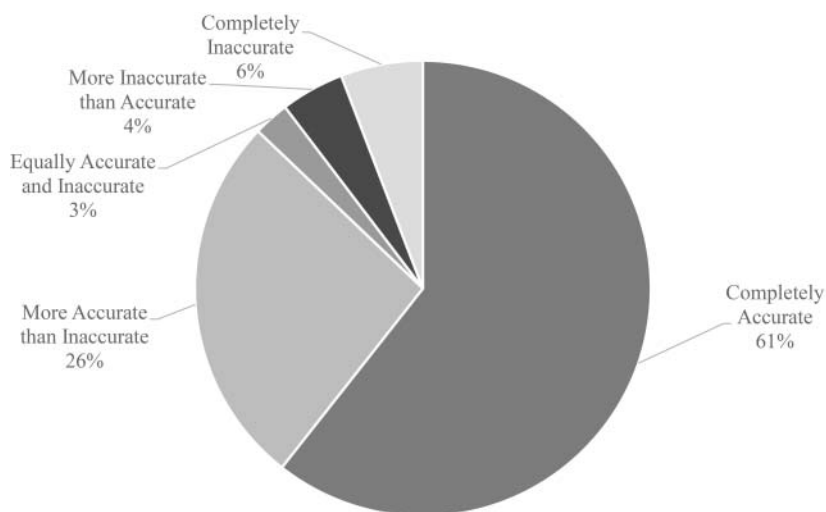


Figure 8 Third Trimester Percentages of “Medical Accuracy”

decision is “thoughtful and informed.” What light do our findings shed on how informed consent laws have been applied in practice? To what extent do informed consent materials comport, or not, with these principles?

First, the provision of detailed information about embryological and fetal development is in accordance with the principle established by *Casey*, that the state can express an interest in fetal life “from the outset of pregnancy.” Requiring women to be provided with information regarding embryological and fetal development from the moment of conception is consistent with this state interest. The fact that all the states that we reviewed provided information about fetal development from the point of fertilization is consistent with the interest of the state in “potential life.”

Second, the provision of embryological and fetal development information is also consistent with the right of the state to express its preference for childbirth over abortion. Most recently, this principle was reaffirmed in the decision of the Federal Appellate Court for the Eighth Circuit in *Planned Parenthood Minnesota, North Dakota, South Dakota v. Mike Rounds* (686 F.3d 889 (8th Cir. 2012)), where the court ruled that the state “can use its regulatory authority to require a physician to provide truthful, non-misleading information relevant to a patient’s decision to have an abortion, even if that information might also encourage the patient to choose childbirth over abortion.”

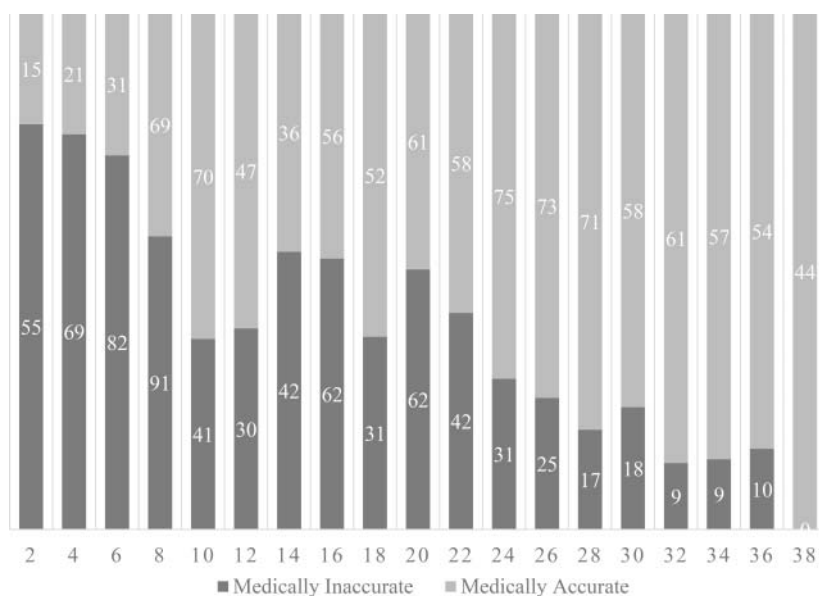


Figure 9 Number and Percentage of Statements by Medical Accuracy and Week of Pregnancy (LMP)

The question raised by our findings relates to the *nature* of the information the state may provide to “encourage” women. While information regarding embryological or fetal development may sway a woman’s decision to choose abortion, this information must be, most fundamentally, medically accurate. Again, as *Casey* specified, the information must be “realistic and appropriate for the woman’s stage of pregnancy,” and state-authored materials must be “objective, non-judgmental and designed . . . to convey only accurate scientific information about the unborn child.” Therefore, although information produced by the state may be “biased” in favor of childbirth over abortion, the state cannot use medically inaccurate information in the service of persuasion. This would be a clear violation of the principle established by *Casey*. The fact that medically inaccurate information is systematically inaccurate in the direction of *exaggerating* the “baby-like” capacities of the embryo/fetus suggests that the state is presenting misinformation about embryological/fetal development in the interest of persuading women to choose birth over abortion.

Third, the level of medical inaccuracy in the information provided to women in informed consent states suggests that, in practice, informed consent laws fail to achieve the purported state interest in ensuring that a

woman's choice is "thoughtful and informed." What level of accuracy is required by the court to ensure that a woman's decision is well informed? Once again, the most recent court ruling on this question has come in the *Rounds* decision. In this case, the court set out to review the constitutionality of a South Dakota informed consent provision that mandated that providers read a statement concerning the "increased risk" of suicide and suicide ideation in women who have abortions. Planned Parenthood challenged the law, arguing that inferring a causal link between abortion and suicide was misleading and untruthful. The appellate court upheld the law based on the principle that the states retained "wide discretion to pass legislation in areas where there is medical and scientific uncertainty" (*Rounds* quoting *Gonzales v. Carhart*, 550 U.S. 124, 163 S. Ct. 1610 (2007)). The court found that the suicide risk that passed this standard as a "medical risk" could simply mean a correlation and did not have to show a causal role.⁸

What might our findings mean for the court's distinction between "medically inaccurate" and "medically and scientifically uncertain" information? Might the levels of inaccuracies found by our expert reviewers be attributable to areas of scientific uncertainty regarding questions of, for instance, brain, eye, lung, or heart development? Might the pattern, for instance, of higher levels of inaccuracy in the first weeks of pregnancy be due to higher levels of scientific uncertainty in the first trimester? Based on the levels of knowledge of embryological development in the standard developmental textbooks (see, e.g., Sadler 2011), there is no reason to think that this would be the case. How might the courts assess the distinction between medically uncertain and medically misleading information? As the court ruled in *Rounds* (686 F.3d at 895–906): "A truthful disclosure cannot be unconstitutionally misleading or irrelevant simply because some degree of medical and scientific uncertainty persists." In any case, it is troubling that the greatest amount of misinformation is found during the gestational period in which the vast majority (over 90 percent) of abortions are performed.⁹

8. The majority opinion noted that the correlation standard was common and was one that should not be changed in the abortion context: "It is a typical medical practice to inform patients of statistically significant risks that have been associated with a procedure through medical research, even if causation has not been proved definitively" (*Rounds*, 686 F.3d at 905).

9. According to the Centers for Disease Control and Prevention's most recent abortion surveillance summary, "Abortion Surveillance—United States, 2011" (Pazol et al. 2014), 64 percent of abortions were performed at or before eight weeks gestation, and 91.4 percent were performed in the first trimester.

While the science of embryological and fetal development continues to evolve, most aspects of human development are well established. Some elements of in utero development naturally vary from pregnancy to pregnancy, but baseline developments generally do not vary beyond the two-week stages established by the medical science of embryology (Sadler 2011). While there may be areas of dispute, medical information provided by the state should be based on medical consensus, and in the absence of consensus such information should not be presented as fact.¹⁰

Conclusion

The original Pennsylvania law challenged in *Casey* contained the following provision, allowing physicians discretion regarding what information to provide pregnant women:

The statute now before us does not require a physician to comply with the informed consent provisions if he or she can demonstrate by a preponderance of the evidence that he or she reasonably believed that furnishing the information would have resulted in a severely [505 U.S. 833, 884] adverse effect on the physical or mental health of the patient. 18 Pa. Cons. Stat. 3205 (1990). In this respect, the statute does not prevent the physician from exercising his or her medical judgment. (*Casey*, 505 U.S. at 884)

The provision of inaccurate medical information to a patient for *any* medical procedure would no doubt have an adverse effect on that patient. By any medical standard, confidence in the accuracy of physician-provided information is central to sound medical care. Even though patients surely question the veracity of information provided to them by physicians (consider disagreements over vaccinating children, for instance), it is deeply problematic for the state to mandate that physicians provide inaccurate medical information to a patient.

In the context of abortion, the need for medical accuracy is even more pressing, since the abortion decision is not just about one's own health but about one of the most fundamentally profound decisions a human being can make—whether to beget another human life. Misinformation that represents the conceptus or embryo, for instance, as having the capacity for sentience or for developmental features close to a fully formed baby might

10. For example, though fetal pain is a politically contentious part of abortion provision, a systematic review of medical evidence on fetal pain finds that fetal perception of pain is unlikely before the third trimester (Lee et al. 2005).

place a deeper emotional burden on a woman seeking an abortion. It is even more concerning when such misrepresentations are authored by the state and delivered by a medical provider—sources that patients rightfully expect to have confidence in as sources of reliable, accurate information. Violating the confidence of a patient to receive accurate information from these sources not only might have “severely adverse” effects on patients but also potentially undermines confidence in the integrity of the health care regulatory and medical provider systems.

To date, federal appellate courts have upheld challenges to informed consent laws in the states. Yet these affirmations have been based on assumptions of the medical accuracy of the information provided to women. Our study suggests that this is not the case. While the principle of stare decisis weighs against the overturning of informed consent laws as a whole, the level of medical inaccuracies evidenced in this study calls for a rethinking of the soundness of the court’s logic in upholding abortion-related informed consent laws.

The facts on which the earlier court cases have been premised—that the state’s mandate of information to women seeking abortion would produce the conditions for a more “mature and informed” choice—may ultimately be proved wrong. The findings of this study illustrate how, once in practice, informed consent laws may in fact produce “misinformed consent” and may, as a result, require the court to rethink the constitutionality of abortion-related informed consent laws as a whole.

■ ■ ■

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References

- Lee, Susan J., Henry J. Ralston, Eleanor A. Drey, John Colin Partridge, and Mark A. Rosen. 2005. "Fetal Pain: A Systematic Multidisciplinary Review of the Evidence." *Journal of the American Medical Association* 294, no. 8: 947–54.
- Pazol, Karen, Andreea A. Creanga, Kim D. Burley, and Denise J. Jamieson. 2014. "Abortion Surveillance—United States, 2011." *MMWR Surveillance Summaries* 63, no. SS11: 1–41.

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- Richardson, Chinué Turner, and Elizabeth Nash. 2006. "Misinformed Consent: The Medical Accuracy of State-Developed Abortion Counseling Materials." *Guttmacher Policy Review* 9, no. 4. www.guttmacher.org/pubs/gpr/09/4/gpr090406.html.
- Sadler, T. W. 2011. *Langman's Medical Embryology*. 12th ed. Philadelphia: Lippincott Williams and Wilkins.

Appendix A

Maps of States with Informed Consent Statutes (as of 2013)



Figure A1 Map of States with Informed Consent Policies

Notes: Dark gray states have active and enforceable informed consent policies. States coded in light gray (MA, TN) had enjoined their informed consent policies.

List of States with Informed Consent Laws

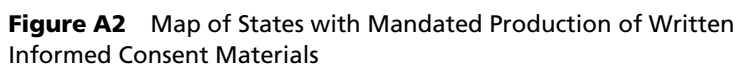
37 States with informed consent statutes: AK, AL, AR, AZ, CA, CT, DE, FL, GA, ID, IN, KS, KY, LA, MA (enjoined), ME, MI, MN, MO, MS, MT, NC, ND, NE, NV, OH, OK, PA, RI, SC, SD, TN (enjoined), TX, UT, VA, WI, WV.

29 States with specific mandated scripts: AK, AL, AR, AZ, GA, ID, IN, KS, KY, LA, MA (enjoined), MI, MN, MO, MS, MT, NC, ND, NE, OH, OK, PA, SC, SD, TX, UT, VA, WI, WV.

8 States with “customary laws”: CA, CT, DE, FL, ME, NV, RI, TN.

23 States with fetal development brochures:* AK, AL, AR, AZ, GA, ID, KS, LA, MI, MN, MO, NC, ND, NE, OH, OK, PA, SC, SD, TX, UT, VA, WV.

* Four States’ materials were not available at the time of our study: IN (booklet not developed until April 2014, past the time scope of this study) and KY, MS, and WI (printed medical materials not available).



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Appendix B: Examples of Informed Consent Statements, Inaccurate and Accurate

Table B1 Examples of Medically Inaccurate Statements by Week (LMP)

Week	Statement
2	Arm and leg buds are present
2	At four weeks, the unborn child is less than 1/100th of an inch
2	Blood circulation begins
2	Bone tissue is growing
2	Buds begin to grow at the limbs: forelegs and arms
2	By five weeks, development of the brain, spinal cord, and heart is well under way
2	Following implantation, the blastocyst is called an embryo
2	The brain and spinal cord begin to form
2	The cells are beginning to grow into groups that will be parts of the embryo
2	The cluster of dividing cells, called an embryo, nests in the lining of the womb
2	The developing embryo is about the size of a pinhead
2	The embryo is approximately .014 inches long, which is the size of the thickness of a standard staple
2	The embryo is less than 1/100th of an inch long
2	The eyes and ears are just beginning to form
2	The fertilized egg attaches to the lining of the uterus
2	The head has formed
2	The heart and lungs are the first organs to form
4	Development of the brain, spinal cord, and heart is well under way
4	Early reflexes develop
4	Eyes are present, but no eyelids yet
4	Fingers grow to the first joint
4	Head and upper body are well developed
4	Nerves are beginning to form
4	The brain develops into five areas, and some cranial nerves are visible
4	The embryo and first nerve cells have formed
4	The spine and head are forming
6	At the other end is a tail bud, which will become the end of the spine
6	At eight weeks, a pregnancy test will be positive
6	Bones of the jaw and collarbone begin to harden
6	Boys have testes
6	Brain activity can be recorded

Table B2 Examples of Medically Accurate Statements by Week (LMP)

Week	Statement
2	The ball of cells digs into the lining of the uterus
2	The ball of cells begins to form layers and fluid-filled spaces
2	Some of the cells will grow into the embryo and other cells will form the placenta
2	Actual size is 1/100th of an inch long (.254 millimeters), about the size of a period at the end of a sentence
2	The embryo is between 1/100th and 4/100th of an inch long at this time
2	The embryo is too small to be seen
2	By the twenty-fifth day the heart will beat
2	The embryo is less than one ounce
4	The placenta will nourish the embryo, then the fetus, for the remainder of its stay in the uterus
4	Heart is forming and begins to beat
4	The embryo is .16 inches in length, which is about the thickness of two nickels put together
4	The major portion of the lung development is yet to occur
4	There are three primary parts of the brain
4	Embryo changes from a flat disk to a curved, C-shaped form
4	The embryo has developed a head and a trunk
4	Development of the brain and spinal cord begins
4	A ridge of tissue forms down the length of the embryo. That tissue will later develop into the brain and spinal cord
4	Tissue forms that develops into vertebra and some other bones
4	The lungs are beginning to form
6	The heartbeat is visible by ultrasound examination
6	The head is large in comparison to the trunk, about half the embryo's length
6	The unborn child's heart rate peaks at about 170 beats per minute and will gradually slow down until birth
6	The embryo is now surrounded by a sac filled with amniotic fluid. The fluid within this sac protects the embryo
6	The umbilical cord joins the embryo and the placenta

Appendix C

Table C1 Medically Inaccurate Statements by Body System Subject

Body System Subject	<i>N</i> of Statements	<i>N</i> of Inaccurate Statements	% of All Statements Inaccurate (Overall)
Activity	298	69	23.15
Extremities ^a	177	53	29.94
General external ^b	320	45	14.06
General internal ^c	555	145	26.13
Head and facial features ^d	326	62	19.02
Size and weight	699	188	26.89
Viability	190	39	20.53

^aLimbs, fingers and toes, nails

^bHair, skin, fat, neck, breasts, tail, sex

^cCardiovascular, respiratory, nervous system, bones, general organs, growth, muscles, kidneys, blood, immune system, digestive, hormones, liver, glands, temperature

^dEyes, face, ears, nose, mouth, head, teeth

Appendix D: State Statutes

Ala. Code § 26-23A-4. **Voluntary and Informed Consent Required for Abortion**

Cal. Com. Code § 14016.8. **California Welfare and Institutions Code**

Ind. Code § 16-34-2-1.1. **Required Circumstances of Legal Abortion**

Ind. Code § 16-34-2. **Requirements for Performance of Abortion; Criminal Penalties**

Mo. Rev. Stat. § 188.027. **Informed consent section of Chapter 188: Regulation of Abortions**

N.D. Cent. Code § 14-02.1. **Abortion Control Act**

S.D. Codified Laws § 34-23A-56. **Scheduling of Abortions—Prior Requirements**

Utah Code 76-7-305. **Informed Consent Requirements for Abortion**