

The Informed Consent Project

In 2013, Cynthia Daniels and a team of researchers at Rutgers University in New Brunswick, New Jersey, founded the Informed Consent Project. Daniels and the researchers assessed the medical accuracy of information within state-authored informational materials for abortion. States give those materials to women who want an abortion, but using their research, the Informed Consent Project found some information from those materials to be inaccurate, misleading, and coercive. The Informed Consent Project gathered a panel of researchers and medical specialists to review the information about embryological and fetal development from twenty-three states' informational materials. They found that approximately one-third of that information was inaccurate. The work of the Informed Consent Project challenges abortion-specific informed consent laws, highlighting medical inaccuracies in state-authored informational materials as evidence that women's consent to abortion may be based on false or misleading statements.

Informed consent is standard practice for any medical procedure and generally requires physicians to tell patients about the medical procedure, its expected outcome, and its potential risks. The 1973 US Supreme Court case *Roe v. Wade* ruled that pregnant women have a constitutional right to accessible and safe abortion, which is a medical procedure to terminate pregnancy. After that decision, individual states began to pass abortion-specific informed consent laws. For two decades after the US Supreme Court ruled on *Roe v. Wade*, courts in the US upheld abortion-specific informed consent laws only if they followed the general principles of informed consent and did not dictate what physicians had to say to their patients. However, in 1992, the US Supreme Court ruled on *Planned Parenthood v. Casey*, allowing individual states to pass laws that regulate access to abortion unless those laws cause an undue burden, which means that states cannot pass laws that infringe upon a person's constitutional rights.

In the case of *Planned Parenthood v. Casey*, the US Supreme Court ruled that states are also allowed to develop informational materials and require physicians to give them to their patients, but that information must be both truthful and non-misleading. However, that decision did not require that informational materials remain unbiased, meaning states can persuade women to not have an abortion through the informational materials. *Planned Parenthood v. Casey* set the standards that informed consent laws and the resulting state-authored informational materials. Daniels and the researchers of the Informed Consent Project were specifically interested in whether the information about fetal development provided in informational materials met the truthful and non-misleading standards set by *Planned Parenthood v. Casey*.

The Informed Consent Project's research focuses on evaluating the medical accuracy of statements about embryological and fetal development. In 2013, the Informed Consent project studied twenty-three states with abortion-related informed consent laws, often called Woman's Right to Know laws. Those laws require the state to develop informational materials about abortion and pregnancy. Woman's Right to Know laws require that physicians provide their patients with the information contained in their state's informational materials as part of the informed consent process. That information may include facts about the development of the embryo and fetus in the woman's uterus, the different types of abortion procedures, the risks of abortion, the risks of carrying a pregnancy to term, and the various alternatives to abortion such as adoption. However, medical organizations have critiqued the Woman's Right to Know Acts of several states for mandating the inclusion of medically inaccurate or misleading information such as linking abortion to breast cancer or increased risk of suicide and claiming the fetus can feel pain at around twenty weeks of pregnancy. For example, in 2013, the American College of Obstetricians and Gynecologists stated several concerns with Texas's informational materials, providing that several claims were medically inaccurate or

misleading.

In 2013, the Informed Consent Project included Daniels and three other women, Janna Ferguson, Grace Howard, and Amanda Roberti, who were doctoral candidates in the Department of Political Science at Rutgers University in New Brunswick, New Jersey. Daniels served as the Chair of Political Science at Rutgers University from 2009 to 2012 and currently works as a professor in the field of reproductive politics and law. In 2012, Rutgers University awarded Daniels their Faculty Diversity Award for her work on racial and gender disparities within academics. Ferguson studied international political economy, feminist institutional analysis, and immigration and citizenship. Then doctoral candidates, Ferguson, Howard, and Roberti studied reproductive politics and law at Rutgers University.

In an interview with Janet Golden for *The Philadelphia Inquirer*, Daniels further discussed the motivation behind the Informed Consent Project. Daniels stated that, in classes related to abortion and the law, undergraduate students often asked her about the abortion-specific informed consent process and contents of state-mandated informational materials. Some of those questions were concerned with who wrote the materials, how the materials differ from state to state, and whether the materials are biased or not. Daniels initiated the Informed Consent Project to address those questions with a specific focus on the accuracy of the information in the materials.

In 2013, Daniels and her research team collected the information materials from twenty-three states that had such materials available. In the interview with Golden, Daniels stated that, as a political scientist, she did not have knowledge of embryological and fetal development. So, Daniels attended the annual meeting of the American Association of Anatomists and recruited seven experts on embryological and fetal development to take part in her study and evaluate the information provided in each set of materials. The experts only knew that the information had to do with embryonic and fetal development, rather than abortion, to reduce bias. Also, based on the US Supreme Court's decision on *Planned Parenthood v. Casey* that informational materials had to be truthful and non-misleading, Daniels and her team created two five-point scales to assess the truthfulness and non-misleadingness of claims about embryonic and fetal development.

The experts gave each statement about embryological or fetal development a score from one to five, based on a scale from true to false and from non-misleading to misleading, where zero meant true and non-misleading and five meant false and misleading. The researchers then analyzed the experts' ratings and came up with three main findings. The first finding was that most of the statements they evaluated about embryological and fetal development were medically accurate. Overall, they evaluated approximately one-third of statements to be inaccurate and also gave the percentage of inaccurate statements for each individual state. For example, the researchers found that North Carolina's informational materials were forty-six percent inaccurate, which was the highest percentage of inaccuracy. In contrast, the researchers found that Alaska's informational materials were fifteen percent inaccurate, which was the lowest amount of inaccuracy. The researchers also found no significant association between the geographic location and political affiliation of each state and the percentage of statements found inaccurate by the panel of experts. For example, Michigan, a left-leaning state, had one of the highest rates of inaccurate statements. In the interview with Golden, Daniels expressed that those findings surprised her and the researchers.

Secondly, the researchers found a large number of medically inaccurate statements about the characteristics of the embryo or fetus concentrated during the first trimester of pregnancy, specifically between weeks two through six of pregnancy. According to the American College of Obstetricians and Gynecologists, most pregnant women who choose to have an abortion do so during the first trimester. Overall, the experts rated forty-five percent of statements about the first trimester to be medically inaccurate, half of those statements being about the second week of pregnancy. However, the experts rated only twenty-nine percent of statements about the second trimester and thirteen percent of statements about the third trimester to be medically inaccurate.

Lastly, the researchers found that a large number of medically inaccurate statements discussed particular body parts and bodily functions at various stages of fetal development. During their study, the researchers divided the medically inaccurate statements into categories based on the developing fetus's different body systems or functions they talked about. Those included statements

about head and facial features, size and weight, activity, and presence of arms, legs, hands, and feet. The researchers state that the medically inaccurate statements characterized the embryo or fetus to seem more human-like. For example, the experts rated a statement that the fetus can blink and is able to cry at sixteen weeks of pregnancy as inaccurate. Also, although some informational materials stated that arm and leg buds are present at week two of pregnancy, the experts deemed that statement to be medically inaccurate, too. The researchers compiled a group of statements that the fetus can survive outside the womb at various stages of pregnancy, and the experts found twenty percent of those statements to be medically inaccurate. For example, the experts found the statement that the fetus has a twenty-one percent chance of survival with neonatal intensive care at twenty weeks to be medically inaccurate.

Daniels stated, in the 2016 interview with Golden, that the Informed Consent Project's findings also surprised other organizations and researchers. For example, the Informed Consent Project interested researchers at the National Partnership for Women and Families who were conducting a related project called Bad Medicine. Bad Medicine documented anti-abortion laws across the country that, according to the researchers, ignored evidence and science and controlled how healthcare providers practiced medicine. Daniels also stated that a woman from South Carolina, who helped author informational materials on abortion, contacted her and wanted to know how she could ensure the materials were medically accurate. Also, Daniels disclosed that her team met with Texas legislators who wanted to introduce legislation to challenge Texas's informed consent laws.

Roberti, another researcher on the Informed Consent Project, states that the study initially reviewed the original version of Texas's informed consent booklet, which was first published in 2003. When the Informed Consent Project released those results to the public, the Texas legislature passed a law mandating updates to their booklet and began a period of revisions. During that time, the Texas Department of State Health Services, or DSHS, invited the public to comment about and propose revisions to the booklet. The Informed Consent Project submitted several suggestions for correcting the inaccuracies they documented in the booklet. However, in a draft of a newer version of the booklet, which the DSHS released in 2016, the Informed Consent Project found that the percentage of inaccurate statements remained about the same. In fact, Daniels stated that the DSHS removed some accurate statements from the old version. In 2019, the Informed Consent Project examined the most, at that time, up-to-date revisions of Texas's informed consent booklet. The researchers found that twenty-five percent of statements about fetal development in the booklet were medically inaccurate.

As of 2021, twenty-nine states have abortion-specific informed consent laws that require the state government to develop informational materials about abortion and physicians to distribute to their patients. Those materials contain a timeline of fetal development with information about the characteristics of the fetus at two-week increments of development accompanied by color pictures or illustrations. Abortion rights advocates have criticized the informational materials in several states, calling the materials misleading and coercive. Primarily, abortion rights advocates criticize the inclusion of information linking abortion to breast cancer in several states' materials. That claim has not been established by researchers, according to the American Cancer Society. Abortion rights advocates also criticize the materials for using biased language. For example, Daniel Grossman of the Texas Policy Evaluation Project reviewed the Texas booklet and criticized the authors' use of the phrase your baby seventy-nine times compared to their combined use of the terms embryo and fetus nine times. Grossman argued that the DSHS used biased language and intended to make women feel bad about their decision.

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