

## How Politically Mandated "Informed Consent" for Abortion Violates Patient Rights to Get True Information

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Informed consent procedures in health care require patients to be fully and honestly informed about a medical procedure and its potential risks and consequences. Patients are supposed to understand what they are getting into, on the assumption that clear and complete information grounded in medical research is the key to protecting patients' rights and making them informed decision-makers about their personal health care.

But what if informed consent procedures become politicized and factually inaccurate? Imagine that doctors convey false nonscientific information about procedures like wisdom tooth removal or open heart surgery: "If you wish to reverse the procedure, it may be possible to re-implant your impacted molar" or "open heart surgery may increase your risk of breast cancer." Such scenarios sound absurd, but they resemble what routinely happens today in distorted informed consent procedures mandated by many U.S. states.

Because abortion is an intensely debated and deeply politicized issue, some state lawmakers have taken the unusual step of dictating informed consent practice, legislating what information is included, who can provide it, how the information is disseminated, and how much time must pass between informed consent and actual abortion procedures. Most notably, lawmakers in 29 states require doctors or staff to give to women seeking abortions particular state-produced booklets that include statements about fetal development and abortion risks. Lawmakers say these booklets – produced and curated by politicians, often without input from doctors or researchers – contain facts intended to help protect patients from making poorly considered choices. But is that true? My research with colleagues examines the medical accuracy of the information on fetal development in state-mandated informed consent booklets – to assess their impact on personal medical decisions and their alignment with previous legal requirements.

## Are Women Getting Accurate Information on Abortion?

Our study analyzes the informed consent materials mandated by 23 of the 29 states for women seeking abortion and collected every statement on fetal development – 896 statements in all – from the state-produced booklets. We recruited a panel of seven experts on fetal development and embryology to review any text pertaining to fetal development and assess the information for medical accuracy, directing them to rate each relevant statement on two separate scales for truthfulness and non-misleadingness. Truthfulness, we instructed the experts, was to mean scientifically accurate and based on biology; non-misleadingness was to mean "giving a correct impression" in accord with the legal precedent set by U.S. Supreme Court's ruling in the landmark case *Planned Parenthood of Southeastern Pennsylvania et al. v. Robert P. Casey et al. (505 U.S. 833 (1992)*). Once we had all the experts' scores, we then collapsed the two scales into a rating on medical accuracy.

The results showed that 31 percent of the statements on fetal development were medically inaccurate. Notably, 45 percent of those inaccuracies were statements about fetal development during the first trimester of pregnancy – the stage when most women get abortions. Inaccuracies were centered on statements about body parts or fetal actions, with the effect of making the fetus seem more baby-like.

## Which States Present Inaccurate Information – and Where Does It Come From?

Conventional wisdom might presume that booklets would be most inaccurate in states hostile to abortion, especially the southern states. Surprisingly, however, we found no regional differences in inaccuracies appearing in state booklets. And there were no evident political differences, either – because states dominated by Democrats and Republicans turn out to be equally prone to include inaccurate statements in

their booklets. Degrees of inaccuracy ranged widely, from a low of 15 percent of booklet contents in Alaska to a high of 46 percent in North Carolina. The states we were able to review had a median inaccuracy rate of 24 percent – meaning that inaccuracies were found in nearly one quarter of the materials presented to the typical patient seeking abortion across all the states in our study.

Our findings had an immediate public impact. Media coverage of our research prompted numerous state department officials to contact us about the accuracy of their informed consent materials, and state health and human services workers have asked how their states rank and asked us to specify which statements in particular were deemed inaccurate. Immediately after this research was made public, the Texas legislature passed a law mandating updates to their booklets and instituted an open comment period to which our research team submitted suggestions for correcting the inaccuracies in more than a third of the contents of that state's booklet. Ultimately, the updated Texas booklet still contained 21 percent inaccuracies – better, but not a complete fix. Other states remain resistant to updating their booklets at all.

Our team would like to understand how informed consent booklets are developed. They are extraordinarily detailed, in some cases mandated to include very specific statements about matters such as the fetus' ability to feel pain. Investigating which medical organizations and special interest groups are involved in producing, reviewing, revising, and disseminating would lead to more complete knowledge about who shapes U.S. reproductive health care and how.

## **Improving Informed Consent for Abortion**

Overall, this study has raised many questions about the involvement of government in medical decisionmaking, especially about abortion. Court precedents indicate that states have the right to protect patients and give them information they feel is germane to abortion decisions, and also say that a state government can prefer childbirth over abortion. Even so, Casey makes it quite clear that informed consent texts must be truthful and non-misleading. Inaccuracies in these booklets may therefore violate the law and states are directly responsible for correcting their materials. As legal cases continue to be argued, it may turn out that today's informed consent laws are in and of themselves unconstitutional interventions in personal and medical decisions. If so, one policy suggestion would be to suspend all such politicized mandates for explanations of abortion – and instead simply require that abortion providers or medical organizations produce their own informed consent booklets based on the best medical evidence and judgments.

Research and data for this brief are drawn from the author's ongoing work with colleagues as part of The Informed Consent Project.