

# Informed Consent, Capacity, and What we Do with Genomic Information

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the Past, Present and Future*

# Informed Consent: Everyday, and Everywhere

If you have any questions concerning the research study, please contact the research team at: [eadietz@asu.edu](mailto:eadietz@asu.edu) (Elizabeth Dietz) or [bhurlbut@asu.edu](mailto:bhurlbut@asu.edu) (J. Benjamin Hurlbut). If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study.

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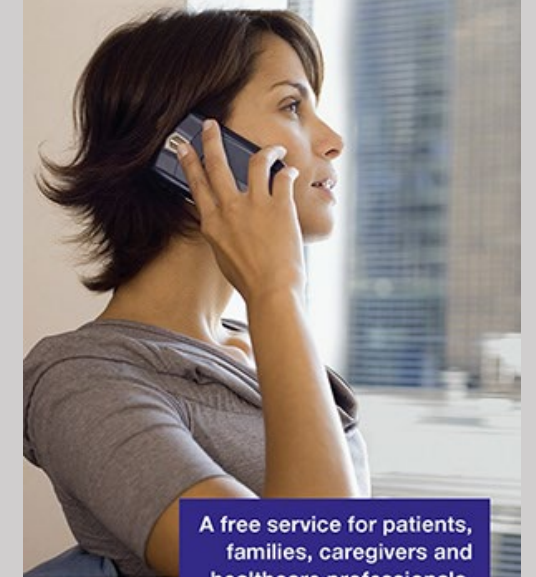
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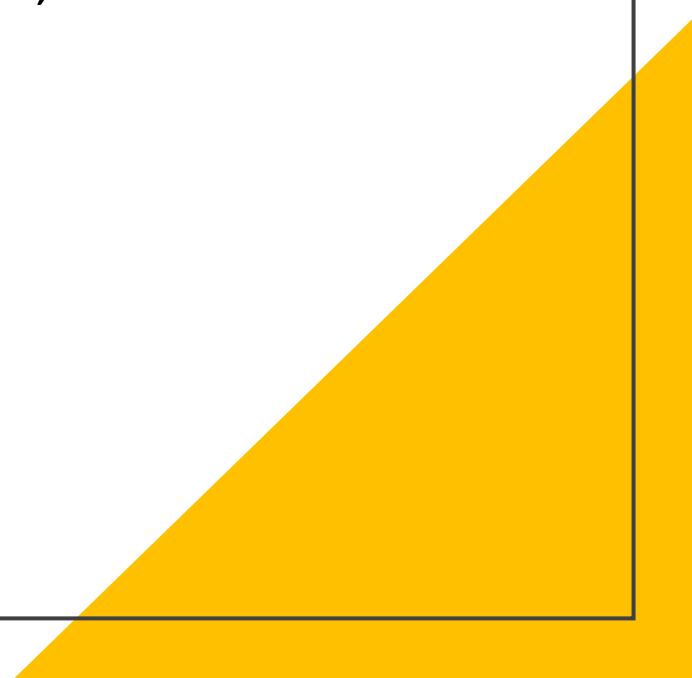
# What is informed consent?

- Epistemic relationship where knowing things authorizes legitimate choosing
  - Key origin story: Tuskegee
  - “Knowing” must be measured: A question of capacity

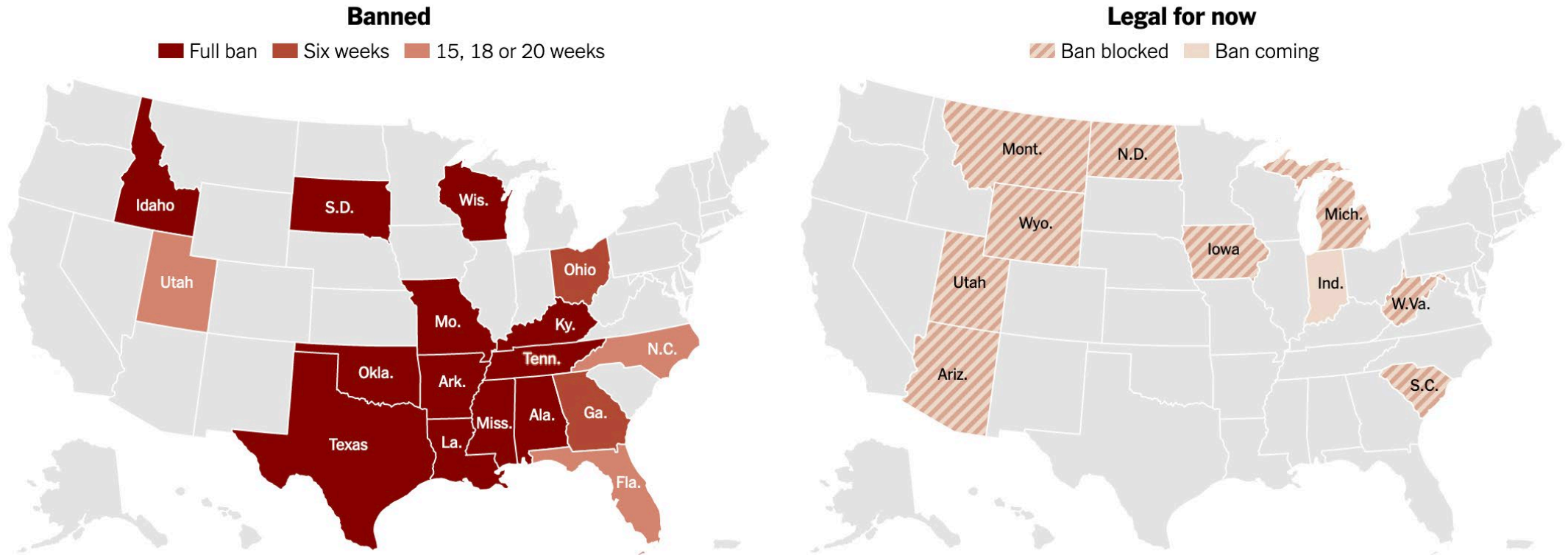
# Why think about informed consent?

- Consent = part of solutions to problems of justice
- Site for the exercise of power
- Used to regulate disability

# Informed Consent For/Against abortion

- Pro-abortion: Informed consent → information for access, consent because healthcare
  - Anti-Abortion: (often false) Information about harms, to constrain choice
  - Not-abortion: Prenatal information acts
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# NYT Map of current and pending abortion bans



<https://www.nytimes.com/interactive/2022/us/abortion-laws-roe-v-wade.html>

# Pro-Abortion Informed Consent

- *Guttmacher Institute*: “Three interrelated elements underlie the long-standing tradition of informed consent: Patients must possess the capacity to make decisions about their care; their participation in these decisions must be voluntary; and they must be provided adequate and appropriate information.”

Guttmacher Institute. “Counseling and Waiting Periods for Abortion,” March 14, 2016.

<https://www.guttmacher.org/state-policy/explore/counseling-and-waiting-periods-abortion>.

- *Center for Reproductive Rights*: “Notably, informed consent does not include biased or directive counselling or the forced provision of information that a woman does not wish to receive, such as the forced viewing of ultrasound images.”

Center for Reproductive Rights. “Law and Policy Guide: Informed Consent.” Accessed July 6,

2022. <https://reproductiverights.org/maps/worlds-abortion-laws/law-and-policy-guide-informed-consent/>.

# Anti- Abortion Informed Consent

- 2021: 28 states with informed consent laws<sup>1</sup>
- Information: waiting times, ultrasound, information re: fetal pain, information about “adoption,” information about fetal anomaly
- 1/3 statements in these laws “medically inaccurate<sup>2</sup>”

1 - <https://embryo.asu.edu/pages/womens-right-know-informed-consent-informational-materials>.

2 - <http://informedconsentproject.com>



# Anti- Abortion Informed Consent

- Normative commitments:
  - Right info → right choice
  - Right choice = not abortion
  - Choice = individual (as resistance to abortion's legality)
  - (it's not really about choice)

# Pro-Information: Kennedy Brownback

## *“Prenatally and Postnatally Diagnosed Conditions Awareness Act,” 2008*

### **SEC. 2. PURPOSES.**

It is the purpose of this Act to—

(1) **increase patient referrals** to providers of key support services ~~for women who have~~ received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

(2) **strengthen existing networks of support** through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and ~~provider outreach programs; and~~

(3) ensure that patients receive up-to-date, evidence-based information about the accuracy of the test.

# What did Kennedy- Brownback do?

- Largely unfunded
- But: State-by-state model legislation → – “prenatal information acts”
  - Aim to provide “evidence-based information” (most states) and “timely and informative counseling” (eg MI, others)

# Endorsement from many corners:

- **“Pro-Information coalition”**

- Information = bipartisan good
- Failure when information is biased, not when framework is used

- **Disability advocates**

- More info about disability = more understanding = less selective termination

- **Reproductive Rights Groups**

- Choice ought to be informed
- “Unlike other legislation Sen. Brownback sponsors, this measure does not include anti-choice rhetoric or policy provisions that would harm women's health. It's our view that the bill offers information and services to expectant women and does not undermine their right to choose.” - NARAL president Nancy Keenan

- **Abortion Opponents**

**at law**


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Prenatal Testing and Disability:  
A Truce in the Culture Wars?

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by Rebecca Dresser

# So what?

- Information is normative and contestable
  - Capacity judgements are implicit but crucial
  - Informed consent does work
  - Worth thinking about regulatory function of informed consent when articulating pathways to genomic justice
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# Thank you!

@devilinthedietz

