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# Informed Consent To Transformative Treatments

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Informed consent should only be expected to provide the known probabilities of various reasonably expected outcomes rather than projecting the subjective personal dynamics a patient may incur after the procedure. Truly transformative experience may foster irreducible epistemic uncertainty. That acknowledgement should not be described as the impossibility of informed consent, because that level of foreknowledge has never been within the scope informed consent. To expect informed consent to overcome the existential uncertainty endemic to the human condition qualifies as "moving the goal posts." Transformative experiences resulting from some medical treatments may result either in unexpected gratification, unanticipated regrets, or some combination of both. But we should not declare that to be a failure of informed consent when that type of foreknowledge has never been a legitimate goal.

Life is full of transformative experiences. A characteristic aspect of human life is the potential for regret after a decision has been made that is irreversible. Informed consent was never meant to resolve that problem inherent in human life. Neither the art nor the science of medicine can cure that.

The Belmont Report is the foundation of modern criteria for informed consent. Nowhere does it require foreknowledge of patient affective states as a condition of valid informed consent (The Belmont Report, U.S. Department of Health and Human Services 1979). The conclusion that absence of such foreknowledge invalidates informed consent moves the goalposts unjustifiably.

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# Informed Consent To Transformative Treatments

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## THE CHALLENGE

Can informed consent to medical treatment be given when not enough information about the treatment and its consequences is available? Daniel Villiger refers to this as the *challenge of ignorance* (Villiger 2025). According to the standard view, valid consent must be voluntary, informed, and given by a competent person (see Bullock 2018). The information requirement is one of the requirements to be met for consent to be valid. If the patient is not informed or does not have enough information about the treatment, she cannot give informed consent. In such cases, her consent cannot make the treatment permissible. Sometimes, patients are not properly informed and are therefore

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unable to give valid consent. In other cases, the issue is not merely that information is withheld, it may be fundamentally unavailable. This seems to occur in situations involving what Villiger (2025) describes as *transformative experiences*, experiences that alter a person's preferences and values in ways that cannot be anticipated by the patient. As Villiger writes:

> An epistemically transformative experience means that we gain knowledge through an experience that is otherwise unattainable (e.g., the sensory phenomenology of the experience). A personally transformative experience refers to an experience that radically changes our point of view, or, to use another term, our core preference. (Villiger 2025, 128)

Consider the example of surrogacy: a woman consents to a surrogacy contract without knowing what it is like to be pregnant or how the experience might alter her values and preferences. Or take the case of someone consenting to a leg amputation, she may not fully grasp what life with only one leg entails. In such cases, it appears that informed consent cannot be given, and therefore, valid consent is also lacking. As a result, the treatment in question cannot be made permissible. However, Villiger argues that this conclusion is mistaken. He contends that informed consent is possible even under conditions of ignorance. To support this claim, he offers two arguments: (1) an empirical argument and (2) a theoretical argument.

Consider first the empirical argument. Villiger cites a study indicating that "our affective forecasting abilities are similar for transformative and non-transformative experiences" (Villiger 2025, 132). He argues that this "seems to indicate that, contrary to Paul's argument, ignorance caused by an outcome's transformative nature does not pose a special problem to ordinary reasoners. In turn, this suggests that the challenge of ignorance does not pose a special problem to informed consent for transformative treatments" (Villiger 2025, 132). However, he cautions that these findings should be interpreted carefully, as it remains unclear whether the forecasting abilities measured truly reflect an adequate understanding of the subject matter.

This is why Villiger turns to a theoretical argument, which explains how informed consent can still be given under ignorance. According to him, informed consent is possible when ignorance is properly addressed by the physician. If the patient understands that certain information is unavailable, and that there is no lack of awareness of a risk or missing fact, the patient can decide whether she consents to the treatment. By disclosing irreducible ignorance and making clear that the physician cannot know any better, the patient "is put in a position to give informed consent" (Villiger 2025, 134). Villiger thus concludes that there is "no reason why the challenge of ignorance should prevent informed consent" (134). The patient knows as much as the physician about the outcome of the medical treatment. The physician does not exert any control over the patient's decision by withholding or distorting information. In light of irreducible ignorance, the patient can decide whether to consent or not to consent to undergo the treatment. As Villiger puts it: "It is then up to the patient to make the final decision and take the risk …" (Villiger 2025, 134).

However, can we truly give informed consent to transformative treatments? Unlike Villiger, I am not convinced that there is a unique informational problem associated with such treatments. Consider the case of surrogacy: a woman who has never been pregnant cannot know firsthand what pregnancy feels like and cannot know whether the pregnancy will change her values and preferences. Still, one can gather information about pregnancy by learning from the testimonies of women who have been pregnant and have participated in surrogacy. We can learn about their physical and emotional experiences, how it felt to be pregnant, and how it changed the preferences and values of the pregnant woman, the challenges they faced, their feelings upon giving the child away, and more. Patients can rely on second-person testimony, physicians' expertise, and empirical data from physicians, for instance, on the percentage of individuals who have regretted undergoing a particular treatment.

Moreover, the relevant information about the outcome of a medical treatment is not limited to its subjective value (whether it feels good or bad). The decision to undergo a treatment also involves objective or intersubjective values that are independent of how the outcome is personally experienced. We often consent to treatment because we believe the outcome has significance beyond its immediate experiential impact. For example, a woman might agree to a surrogacy contract because she believes it is valuable to help a couple who cannot have children. The truth of that belief does not depend on how it feels to be pregnant. Therefore, even if a patient cannot anticipate how the outcome will feel or might alter her values and preferences, information about the treatment that provides patients with reasons to consent or refuse to consent can still be gathered and assessed.

## WHY IS INFORMED CONSENT REQUIRED?

But what if the ignorance is truly irreducible? Could informed consent still be given in such a case? While a patient could certainly *give* consent, it is less clear whether that consent would qualify as *informed*. The answer depends on the purpose that the required information is meant to serve. Villiger identifies several such purposes:

a. Enabling the patient to make an autonomous decision (Villiger 2025, 133);
b. Allowing the patient to make a decision that aligns with her values (Villiger 2025, 133);
c. Helping the patient make a good decision (Villiger 2025, 133).

Which of these aims can be achieved when consent is given under conditions of ignorance? A patient might still make an autonomous decision if autonomy is understood merely as freedom from external control. However, it is unclear whether this minimalist understanding of autonomy is what informed consent is supposed to protect. Information is required not to enable the patient to give permission to the physician to undertake the treatment, it is rather required to enable the patient either to act in a way that aligns with her values or to act in her interest. As for these two aims, consent given under ignorance does not allow the patient to make a decision that aligns with her values or ensures a good outcome. If the information requirement for consent is meant to support one of these aims, value alignment, or the well-being of the patient, then informed consent cannot be given in the face of irreducible ignorance.

Moreover, given that physicians are obliged to act in the best interests of their patients, they would have no reason to believe that they would fulfill this duty if a treatment decision had to be made without sufficient information. Even if one adopts Bromwich and Millum's view (Millum and Bromwich 2021, as cited in Villiger 2025), that valid consent requires only that the patient understands what she is consenting to (e.g., surrogacy or leg amputation), it remains unclear whether physicians would be permitted to undertake the treatment. The physician might have the patient's permission (the permission was given by the patient's consent). However, the physician would still not be permitted to undertake the treatment if it were only permissible when in the patient's best interest. Without information about potential benefits and risks, they could not determine whether performing the treatment serves the patient's interests.

However, as I have argued above, relevant information about a treatment can typically be gathered, even in the case of transformative treatments. Patients need not rely on inaccessible first-person experience. Instead, they can draw on second-person testimony, physicians' expertise, and empirical data.

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