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## The Social Value Misconception and the Ethics of Enrollment

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Research ethicists have long worried about the deleterious effects of participant misconceptions on enrollment decisions—ranging from false beliefs about a trial's investigational nature to false beliefs about the expected health benefits of enrollment.<sup>1</sup> In their excellent article, Jake Earl, Liza Dawson and Annette Rid add another to the list (Earl, Dawson and Rid 2025). The Social Value Misconception (SVM) is marked by false beliefs about a trial's expected benefit to others. These false beliefs sometimes lead participants to enroll in research studies they would otherwise refuse. SVM undermines the quality of these consent decisions. The authors are right to think this novel misconception raises similar concerns to those with which we are already familiar. However, just as with previously identified misconceptions, the nature and degree of ethical concern—and what ought to be done to prevent, mitigate, or make compensation for its effects—is not straightforward.

In this commentary, I draw on joint work with Joseph Millum to analyze the ethics of enrolling participants with SVM into clinical research. I argue that it is important to distinguish instances with the potential to invalidate consent from those that merely undermine good decision-making.

The informed consent process serves multiple functions, but two are central, or so Millum and I argue (Bromwich and Millum 2017). The primary aim is to obtain *valid* consent. When clinical research involves acts that would otherwise be rights violations, obtaining a participant's valid consent is an ethical (and legal) requirement. Were researchers to proceed without it, they would violate a participant's rights, and that would be *seriously* morally wrong. The secondary aim is to help a participant make a good enrollment decision. It is better for them if they make a decision that aligns with their interests and values, but this

aspiration could not be a requirement. Competent participants have the right to make their own decisions. Researchers are not permitted to require them to make a good decision—that is, the decision the researcher thinks the participant should or even the decision the researcher thinks the participant would if their decision-making could be improved. With that said, researchers also have duties of beneficence. They have a (limited) obligation to help improve participant enrollment decisions.

Delineating the central aims of the informed consent process is instructive here. Proceeding on invalid consent *wrongs* the participant, whereas proceeding on poor decision-making (but valid consent) does not. Instances of SVM with the potential to invalidate consent are *far more* concerning than those that merely undermine good decision-making.

This is why the most pressing ethical question is: does SVM invalidate consent? The answer to this question depends, in part, on what needs to be understood for consent to be valid. There are maximalist and minimalist views of understanding.

On a maximalist view of understanding SVM invalidates consent. Maximalists argue that valid consent requires the consent giver to understand either everything that is in their interests (Wendler and Grady 2008) or everything that would be relevant to their enrollment decision (Faden and Beauchamp 1986). It follows that many participants with SVM will not understand enough to waive their rights.

This implication ought to spark alarm given just how widely held maximalist views are. If a participant's failure to understand these facts *really* invalidates their consent, the prevalence of SVM ought to be determined as a matter of urgency, participants in hyped and low-value research should be re-consented, and the research community should consider

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appropriate reparations for those whose rights have been violated. However, as Millum and I observe, previously identified misconceptions have failed to ignite this much alarm (Millum and Bromwich 2021). This implies that many researchers and research ethicists either doubt the necessity of valid consent (unlikely) or doubt that this information really needs to be understood to give valid consent (likely).

On a minimalist view of understanding SVM does not invalidate consent. Millum and I argue that valid consent only requires that the person giving it understands *how* to give it, *that* they are giving it, and *what* rights they are waiving when they give it (Millum and Bromwich 2018). Minimalism justifies the lack of alarm. After all, it is perfectly possible to know that you are giving consent and what you are giving consent to while having false beliefs about the study's expected social value.

However, minimalism about understanding does not settle the matter of validity. Even when a participant understands enough, their consent can be invalidated by inappropriate disclosure (Bromwich and Millum 2015). Some disclosure practices that produce SVM have the potential to invalidate consent (Bromwich and Millum 2017).

Millum and I think that researchers invalidate consent when they exercise illegitimate control over a participant's enrollment decision. (Bromwich and Millum 2015). The authors focus on cases in which SVM is controlling—that is, instances in which “false beliefs about the expected social value of studies lead them to decide to enroll” (p. 2) So, with the control condition met, the key question for the validity of consent under SVM is whether the illegitimacy condition is met.

What does it mean to say that disclosure is illegitimate? It means that it is wrongful. Participants have a right not to be deceived in the informed consent process, and yet some are wronged by deceptive disclosure practices. These practices are rarely marked by outright lies or malevolent intentions. They are typically omissions or misrepresentations that predictably mislead participants about facts they would expect to be told. Like the authors, Millum and I have analyzed the language of “cure” in HIV cure-related research (Bromwich and Millum 2017). It has been used to describe proof-of-concept trials testing the safety of high-risk interventions with no prospect of directly curing a participant's HIV or developing interventions that could cure HIV in the near future. It would be perfectly reasonable for a participant to think that the researchers would only use the language of cure if those were the expected benefits. The use of this language, in this context, was (and still is) deceptive.

SVM among these participants is likely the result of wrongful deception.

Contrast this with another case of SVM. The authors discuss Alan Wertheimer's “completion misconception” (p. 3). After being diagnosed with leukemia, Wertheimer enrolled in clinical research partly for altruistic reasons. However, due to poor recruitment, his study was eventually terminated. Although non-completion risks are known, Wertheimer had not anticipated them, and they were not disclosed during the consent process. He later argued that they ought to be because participants ought to be told “whatever information can reasonably be expected to be relevant to an intelligent decision about participation” (Wertheimer 2014, 128). However, failing to disclose the risk of non-completion is not deceptive. Of course, it *would be* if this information were routinely disclosed, but it is not. Wertheimer's researchers had good reason to think that most participants would not reasonably expect to be told it given existing practices.

Much of this analysis hangs on whether participants were told, or whether it was implied, that the clinical research they enrolled in was socially valuable. If they were told it was when it was not, or if that was implied by the language used, then the disclosure was deceptive. When deceptive disclosure is controlling, participant consent is invalid. This is why we should worry about SVM among HIV-cure related participants. However, as Wertheimer's case illustrates, not all participants controlled by SVM are victims of wrongful deception. In cases like this one, participant consent might well be valid even if SVM undermines the quality of the enrollment decision. Moreover, since enrolling these participants does not violate their rights, if researchers have disclosed what they know, believe to be relevant, and judge a participant would reasonably expect to be told in an understandable manner, then they have discharged their duties of disclosure. Any extra duty to facilitate *good* enrollment decisions is limited by reasonable demands on their time and resources.

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## OPEN PEER COMMENTARIES



## Gender Norms, Altruism and Susceptibility to the Social Value Misconception

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Earl, Dawson and Rid (2025) present a compelling case for the potential role of the social value misconception (SVM) in compromising consent and decision-making in research. I agree with the authors that, given we worry about therapeutic misconception and the preventative misconception, we should pay attention to the SVM. I also agree that research with very low social and/or scientific value should ideally not be approved by an ethics committee in the first place; and that accurately predicting the social value of any given research study is problematic due to the incremental and uncertain nature of the research process. Finally, I share the authors' view that there are broad challenges with respect to consent for research and that we have limited understanding about how people actually make decisions to participate in research. Evidence suggests many research participants don't fully read, understand or remember participant information documents; and trust in specific clinicians, researchers or institutions seems to be highly influential in decisions to participate in research. Given these

caveats, we shouldn't be pedantic about the supposed purity of informed consent in research, nor alarmist about the risk of SVM. SVM is one of the many errors in reasoning which can undermine informed consent.

Nonetheless, the SVM is both conceptually and pragmatically interesting. SVM provides a useful lens for considering the underlying motivations for research participation and challenges us to provide potential research participants with meaningful and accessible information to improve decision making and agency. I support Earl et al.'s call for more empirical research to understand how SVM operates in practice. In this commentary, I will focus on the influence of gender norms regarding altruistic behavior with respect to the SVM and decisions to participate in research.<sup>1</sup>

Sex and gender should be systematically addressed across all stages of research, which includes thinking about how SVM may differentially impact men and women. Despite decades of advocacy for equitable inclusion of women in clinical research, significant disparities persist in the types of studies that men

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<sup>1</sup>For this commentary, I will use the terms "male" and "female," "men" and "women" as if they represent binary categories. This approach simplifies the complex realities of sex and gender and does not account for diversity in biology and experiences of people who are intersex or transgender or those whose identities and orientations fall outside of heteronormative frameworks.