



## “Some Greater Good”

### Scientific Value, Self-Determination, and Informed Consent and Informed Closure

The data to promote an evidence-based research protections initiative is mounting.<sup>1</sup> However, there is an “absence of a substantial literature on research participants’ perspectives on [research] ethics.”<sup>1,2</sup>

#### Method

Focus groups • 24 adult participants • Eligibility: current or previous volunteers for SBER and/or biomedical studies • Clinical trial volunteers excluded

#### Findings

Participants agreed with established human subject research protections practices regarding consent, risk, and autonomy. However, before they consent, they would also like to know if the research will contribute to a greater scientific or public good, and after the study has concluded, they want to be informed about the results, which I term “informed closure.” I argue that the underlying ethical concern for participants is the *welfare of the self*, a concern which arises from the late-modern subjective meaning of personhood.

#### Data



“I think a study needs to have some value ... [Y]ou don’t do research just for something to do. Should have some end result value for somebody.”

“[I want to know that the researcher’s] interest is in doing the research that involved some greater good – some real concern for me.”

“If you can’t contribute [financially], maybe you can participate in the study just as another way to help out a cause that you believe in.”

“[The consent form] didn’t answer enough questions for me, and I said very straightforward to them, ‘You’re not making a good enough pitch here. You know, I don’t understand why you want [a sample of my DNA] and what you’re going to do with it. *How would it be benefitting society? And unless you can sell this to me better, I’m not going to consent to this part of the study.*’ And they couldn’t sell it better ... [W]hen people want information, you should be able to give them the whole package.”

“People are definitely interested in seeing the results of what they were in.”

“Yeah, [knowing the results is] one satisfaction that you could get out of participating in research, but I haven’t. I’ve been involved in a lot of studies, and I haven’t seen the results.”

“I’ve participated in numerous studies. I guess I was a little disappointed because I never learned the results of the studies.”

“I think they do have an obligation – should have an obligation to let you know what the results are.”

#### Theory



Empirical research on research protections has provided little by way of explanation and theory.<sup>1</sup> However, theory is necessary to more completely grasp the meaning of what these participants said and want.

The changing landscape of research oversight includes the changing subjective meanings of personhood. Late-modern American culture has given rise to ideals of radicalized self-determination, a new subjective experience of personhood, what some call “reflexivity” and “reflexive” individuality. The following are aspects of the reflexive individual as a pure type:

1. “The self is seen as a reflexive project, for which the individual is responsible ... We are, not what we are, but what we make ourselves.”
2. “The reflexivity of the self is continuous, as well as all pervasive. At each moment, or at least at regular intervals, the individual is asked to conduct a self-interrogation.”
3. “[S]elf-identity, as a coherent phenomenon, presumes a narrative ... The reflexive project of the self ... consists in the sustaining of coherent, yet continuously revised, biographical narratives.” Self-narratives are revised in light of self-interrogation.<sup>3</sup>

Participants blurred the distinction between respect for persons and beneficence by expanding the idea of beneficence to include *welfare of the self*. This is because participation can be consequential in what an individual makes of his or her self.

1. While participants want free choice to participate, they also desire information on how their choice relates to the self. Knowing whether the research serves “some greater good” aids participants in making a purposeful choice, or more precisely, a responsible reflexive action for oneself.
2. What I call “informed closure” also helps participants evaluate their exercise of autonomy. Informed closure aids the participant in the process of continuous self-interrogation.
3. In addition, informed closure aids the integration of participation into participant self-narratives. Informed closure helps sustain the autobiography of self as research participant.

#### Action



Conceiving late-modern personhood in terms of reflexivity asks that we see research participation not as an isolated event but a part of the individual’s flow of life, an element in one’s creation of self-identity.

As such, research participation can involve risks and benefits for the participant’s self, the project of radical self-determination. Junk science poses a risk to responsible self-creation. Lack of closure obstructs continuous self-interrogation and desired narrative cohesion.

Based on the data and theory, I offer three quality improvement initiatives for HRPPs to better address the welfare of the late-modern participant’s self.

1. Support efforts to improve science communication and scientific literacy, so participants and potential participants can better judge research and its possible importance.
2. Encourage investigators to provide to potential participants realistic descriptions of the scientific value of the research as part of the consent process, including its realistic contribution to current scientific knowledge, its realistic audience, and its realistic possible contribution to the public good. I am not suggesting IRBs make determinations based on this information.
3. “Establish a process for reporting results [as well as orphan studies] to individual research participants,” as feasible and appropriate.<sup>4</sup>

#### Citations

1. Nicholls, Stuart G. et al. 2015. “A Scoping Review of Empirical Research Relating to Quality and Effectiveness of Research Ethics Review.” *PLOS One* 10(7): e0133639. doi: 10.1371/journal.pone.0133639
2. Graham, Jenny, Ini Grewal, and Jane Lewis. 2006. “Ethics in Social Research: The Views of Research Participants – Technical Report.” *Government Social Research, UK*, p. 10.
3. Giddens, Anthony. 1991. *Modernity and Self-Identity*. Stanford University Press, Ch. 2 and p. 5, 75, 76.
4. Billings, Joanne et al. 2015. “Implementing the Recommendations of the External Review of the University of Minnesota Human Research Protection Program: Work Plan,” p. 48. Accessed June 11, 2015 < <http://research.umn.edu/advancehsr/documents/workplan-final.pdf> >

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