



"Some Greater Good" Scientific Value, Self-Determination, and Informed Consent and Informed Closure

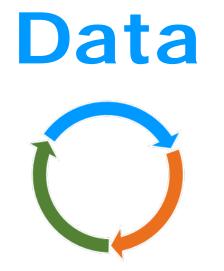
The data to promote an evidence-based research protections initiative is mounting.¹ However, there is an "absence of a substantial literature on research participants' perspectives on [research] ethics."^{1,2}

Method

Findings

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

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.



"I think a study needs to have some val ... [Y]ou don't do research just for something to do. Should have some er result value for somebody."

"[I want to know that the researcher's] interest is in do 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 ou cause that you believe in."

"[The consent form] didn't answer enough questions me, and I said very straightforward to them, 'You're n 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 n better, I'm not going to consent to this part of the stud And they couldn't sell it better ... [W]hen people want information, you should be able to give them the who package."

"People are definitely interested in seeing the results what they were in."

"Yeah, [knowing the results is] one satisfaction that y could get out of participating in research, but I haven I've been involved in a lot of studies, and I haven't se the results."

"I've participated in numerous studies. I guess I was little disappointed because I never learned the result the studies."

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

lue	has provided little by way of
nd	theory. ¹ However, theory is r completely grasp the meanin participants said and want.
loing e	The changing landscape of research oversigh changing subjective meanings of personhood American culture has given rise to ideals of ra determination, a new subjective experience o some call "reflexivity" and "reflexive" individua
ut a	are aspects of the reflexive individual as a pu
for Not	 "The self is seen as a reflexive project, for responsible We are, not what we are, but w ourselves."
101 5 5	2. "The reflexivity of the self is continuous, as At each moment, or at least at regular interva asked to conduct a self-interrogation."
me dy.' ot ole	3. "[S]elf-identity, as a coherent phenomenon narrative The reflexive project of the self sustaining of coherent, yet continuously revise narratives." Self-narratives are revised in light interrogation. ³
s of /ou	Participants blurred the distinction between re and beneficence by expanding the idea of ber <i>welfare of the self</i> . This is because participati consequential in what an individual makes of
n't. een	 While participants want free choice to partic desire information on how their choice relates whether the research serves "some greater ge in making a purposeful choice, or more precis
s a ts of	 reflexive action for oneself. 2. What I call "informed closure" also helps patheir exercise of autonomy. Informed closure the process of continuous self-interrogation. 3. In addition, informed closure aids the integrint participant self-narratives. Informed closure autobiography of self as research participant.

Empirical research on research protections explanation and necessary to more ng of what these

> ht includes the Late-modern adicalized selff personhood, what ality. The following ire type:

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articipants evaluate aids the participant in

ration of participation ire helps sustain the

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.

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. <u>I am not suggesting</u> 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.⁴

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

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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Based on the data and theory, I offer three quality improvement initiatives for HRPPs to better address the welfare of the late-

Citations

^{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.

^{3.} Giddens, Anthony. 1991. *Modernity and Self-Identity*. Stanford University Press, Ch. 2

^{10.}

and p. 5, 75, 76.