Published in final edited form as:

Am J Bioeth. 2016 October ; 16(10): 64–66. doi:10.1080/15265161.2016.1214325.

Shared Governance Embedded in Population Ethics Can Enhance Health Equity Research at both Micro- and Macro-levels

Stephen O. Sodeke, PhD, MA and

Tuskegee University National Center for Bioethics

Clayton C. Yates, PhD

Tuskegee University, Department of Biology and Center for Cancer Research

In their article, “**Governance of transnational global health research consortia and health equity**,” Pratt and Hyder (2016) proposed four ethical requirements connected to shared health governance in attempts to structure, monitor, and assess how well the activities of such consortia promote health equity. The requirements include: (1) shared sovereignty leading to shared decision-making that is inclusive and deliberative, (2) shared resources ensuring that resources are fairly allocated and used efficiently to advance global justice, (3) shared responsibility ensuring that different actors take on different duties to advance justice based on their functions, and (4) collective accountability ensuring shared selection and monitoring of equity-oriented indicators and outcomes. Properly applied, these should further the ideals of global justice in that they will reduce inequalities in health of the worst-off. We agree. We submit, though, that, as a matter of justice, these ethical requirements are consistent with what should happen at a micro level for consortia with similar concerns about health equity research engaging the less well-off.

Drawing on the works of others (Ruger 2011, 2012; Gostin 2012; Pogge 2008) on global governance and on the publications of capability theorists (Nussbaum 2006, 2001; Venkatapuram 2011), the authors applied an account of governance called “shared health governance” embedded in “the health capability paradigm” in order to provide guidance on how to structure research consortia that advance health equity. They identified the workers as interested in the “capabilities necessary for individuals to lead a life of human dignity and what is required to produce and sustain these capabilities” (Pratt and Hyder 2016). Their well-taken point is that the workers made it an obligation to “assist across national borders” as necessary, but insufficient, without defining the kind of “governance arrangements” that make the capabilities possible or sustain them. We concur that both are necessary. Furthermore, the authors observed that the “accountability for reasonableness” (Daniel and Sabin 2002) and the “empowerment conditions” (Gibson et al 2005) can be useful in ensuring fairness, inclusiveness, and reducing power differences that stunt socially acceptable, priority-setting decisions. We surmise that these enabling conditions should also function at a micro level. Thus, what Pratt and Hyder (2016) advocated in theory—*shared governance*, we attempted to put into practice as *governance embedded in the concept of population ethics* in our Center for Translational Science Award (CTSA) consortium, with the Center for Clinical and Translational Science (CCTS) serving as the hub institution.

Pratt and Hyder (2016) argue that, to further the ideals of health justice, “the governance of global health research consortia must serve to ensure consortia activities help to reduce worst-off individuals’ gap in health status from an optimal level,” citing three elements of research consortia—priority setting, capacity building, and research translation. These three link consortia activities to the ends of justice. We agree. At the micro level, where the often poorly resourced, teaching-intensive minority institutions are, all three elements are relevant in advancing the goals of health justice. For the less well-off, and the often poorly resourced minority population that we represent, priority setting will ensure that the major causes of our health shortfalls are not ignored. Capacity building has the potential to support minority research that will reduce diseases that affect our well-being, the services needed to reduce their negative effects on health, and the social determinants of health. Translation of this research will provide benefits, and what we learn by being members of the consortium will be shared in ways that strengthen ownership of our health and well-being. The literature does not lack these aspirations; what is lacking is the will to institute, promote, and sustain shared governance. The concerns and recommendations of Pratt and Hyder (2016) for countries with low-to-medium-income, which, at the macro-level, are worse-off in health, resonate with our recent efforts, at a micro level, to infuse bioethics into a Partnership of 11 research-intensive majority and teaching-intensive minority institutions, of which the Tuskegee Bioethics Center is a part.

The continuing concern for the well-being of the less well-off minority population we represent, the disparities in health that still exist, and the need to achieve health equity through translational research by working with research-intensive, resource-rich institutions has stimulated Tuskegee University scientists to excel, and the Tuskegee Bioethics Center, which has the ethical obligation to assist, to join the Partnership in 2014 and to secure, in 2015, funding from the NIH for a CCTS based in the University of Alabama at Birmingham. In efforts to utilize the Partnership for effective and efficient consortium outcomes, the Partnership’s External Advisory Committee encouraged development and implementation of network activities. They underscored the value of clear processes of working together, including democratic considerations, prioritizing efforts, fair programmatic decision-making, and endorsement or ratification of decisions for implementation. To this end, three models of governance were proposed to cover network-based operational meetings, network-based priorities and strategy meetings, and standing or ad-hoc research domain-oriented meetings. At this point, the Bioethics Section, through the training academy of our Partnership, buttressed the ongoing discussions on models of governance and the idea of sharing it equitably, proposed, sought, and secured approval to engage Partnership members in a one-day reflection on activities.

We considered theoretical population ethics (Encyclopedia of Bioethics 2004) and the works of Rawls 1999; Dickert 2009; Bies 1987; Bies, Shapiro, and Cummings 1988; Tjosvold and Wisse 2009; Lawrence-Lightfoot 2000; Rubin et al. 2012; Burke et al. 2013; and Mezirow 2000. From these, we formulated a training plan to address the essential elements of governance. Population ethics is the philosophical study of ethical problems concerning populations. The value and moral desirability of populations are usually investigated particularly when these populations vary in terms of personal identity (the populations compared may contain different people), number (the populations may be of different sizes),

and quality of life (people in these populations may be at different levels of quality of life or well-being). The premise of population ethics suggests that our beliefs are inconsistent in cases where the number of people and their welfare varies (Encyclopedia of Bioethics 2004). Applied to our context, this premise suggests that, when groups (researchers and affected communities) different in number, entrenched values, and quality of life become partners to address disparities in health, procedural and interactional justice demands that the power and resource differentials that exist be managed equitably. We reasoned that a check and balance on governance activities should become a “normative state of action” in order to have an efficient, effective, and successful Partnership. To this end, we designed and implemented a one-day intensive bioethics dialogue session to infuse Integrative Bioethics into our CCTS Partnership. We focused on the ideas of respect and power-sharing in research partnerships. The aim of the dialogue was to assist participants in examining (1) the “idea of respect in research partnerships” and the relational ethics it calls for, (2) the “bioethics of power-sharing”, (3) the type of leadership ethics that promotes the value of interdependence in research, and (4) the type of transformative knowledge, skills, and attitude that anticipates, addresses, and resolves issues of conflicts, unnecessary stress, imposition of the will of the majority on the minority, and the tyranny of the majority in live experiences and professional practice. The interactional and procedural approaches embedded in population ethics now being used to engage consortium members mirror those suggested by the authors of the target article. They indicate that, in efforts to give voice to the less well-off, the shared governance is malleable and scalable to enhance health equity research.

We concur with the authors that, as a matter of justice, members of research-intensive institutions have an obligation to assist in the teaching of minority members. This is supported by Young (1990; 2000; 2006). To Young, injustice arises when people are deprived of the means to develop and exercise their capacities. We add that, at the micro level, mindful that limited resources make for tough decisions, the nevertheless well-resourced, research-intensive institutions have the obligation to assist and sustain, in the less well-off, teaching-intensive minority institutions, research scientists who have the capacity to excel when given the opportunity. To do less would be unjust.

Pratt and Hyder (2016) proposed a checklist to promote governance of consortia and advance the well-being of those with worse health. We find that the checklist is adaptable at the micro level, where the concerns are similar. The guidance espoused for the macro-level is therefore scalable, and can be employed to evaluate the governance practices being used to promote health equity. Our CCTS consortium is young, but what we do may have effects on the future of health equity in our population. As we progress, the checklist will provide opportunities to reflect on whether or not the governance practices in use are consistent with the goals of justice. It will enable us to assess how consortium members are faring and determine where improvement is needed. Others concerned about health equity through research may learn from our experience.

References

- Bies RJ. Beyond “voice”: The influence of decision-maker justification and sincerity on procedural fairness judgments. *Representative Research in Social Psychology*. (17):3–17.

- Bies RJ, Shapiro DL, Cummings LL. Cummings. Causal accounts and managing organizational conflicts: Is it enough to say it's not my fault? *Communications Research*. 1988; (15):381–399.
- Burke JG, Hess S, Hoffmann K, Guizzetti L, Loy E, Gielen A, Bailey M, Walnoha A, Barbee G, Yonas M. Translating community-based participatory research principles into practice. *Progress in Community Health Partnerships Summer*. 2013; 7(2):115–22. DOI: 10.1353/cpr.0025
- Daniels, N.; Sabin, J. *Setting limits fairly: Can we learn to share scarce resources?*. Oxford: Oxford University Press; 2002.
- Dickert N. Re-Examining Respect for Human Research Participant. *Kennedy Institute of Ethics Journal*. 19(4):311–338.
- Elements of Population Ethics. *Encyclopedia of Bioethics*. The Gale Group, Inc; 2004.
- Gibson JL, Martin DK, Singer PA. Priority setting in hospitals: Fairness, inclusiveness, and the problem of institutional power differences. *Social Science & Medicine*. 2005; (61):2355–2362. [PubMed: 15950347]
- Lawrence-Lightfoot, S. *RESPECT: An Exploration*. Perseus Books; Cambridge, MA: 2000.
- Mezirow, J. *Learning as Transformation: Critical Perspectives on a Theory in Progress*. San Francisco: Jossey Bass; 2000.
- Pratt, Hyder. Governance of transnational global health research consortia and health equity. *American Journal of Bioethics*. 2016; (17):1–37. Target Article UAJB-2015-0008.R2.
- Rubin CL, Martinez LS, Chu J, Hacker K, Brugge D, Pirie A, Allukian N, Rodday AM, Leslie LK. Community-engaged pedagogy: a strengths-based approach to involving diverse stakeholders in research partnerships. *Progress in Community Health Partnerships*. 2012; 6(4):481–90. DOI: 10.1353/cpr.2012.0057 [PubMed: 23221294]
- Tjosvold, D.; Wisse, B., editors. *Power and Interdependence in Organizations*. Cambridge University Press; 2009.
- Young, IM. *Justice and the politics of difference*. Princeton: Princeton University Press; 1990.
- Young, IM. *Inclusion and democracy*. Oxford: Oxford University Press; 2000.
- Young IM. Responsibility and global justice: A social connection model. *Social Psychology & Policy Foundation*. 2006; 23(1):102–30.