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Bioethics and the sociology of trust: Introduction to the theme

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We were honored when the editors of *Medicine, Health Care and Philosophy* invited us to edit a collection of articles on sociology and bioethics. Had this invitation been issued a decade ago, it is likely that we would have collected a number of articles that argued for the inclusion for sociology in the collection of disciplines that make up bioethics. Fortunately, we are now past the point where that argument must be made: for better or for worse, the social sciences are now part of the bioethical enterprise. Of course (as sociologists would predict) the place of social science in bioethics varies by cultural and social context. In the Netherlands and Belgium the creation of "empirical bioethics" has given social science an established voice in the bioethical conversation (Borry, Schotsmans and Dierickx, 2005; Van der Scheer and Widdershoven, 2004). In North America and the UK, social science methods are widely used in bioethics, but social scientists remain, to a certain extent, strangers to the field[1] (Hedgecoe, 2004; De Vries, 2004).

There are advantages to both insider and outsider statuses. We North Americans who stand at a distance from bioethics can take comfort in Simmel's (1950, pp. 402-408) observation that the stranger "is freer practically and theoretically… he surveys conditions with less prejudice [and] is not tied down in his action by habit, piety, and precedent." Simmel pointed out that those who do not "own the soil" are in a unique position, one that combines nearness and distance, indifference and involvement, a social location that allows them to become the recipients of a "most surprising openness" from group members. On the other hand, there are undeniable benefits that come with "owning the soil" of bioethics. The collaborative work that gets done under the rubric of empirical bioethics moves the important ideas of philosophical bioethics into the real world of medicine and medical research where human beings live and work, and help and harm each other (Molewijk et al., 2003; Borry, Schotsmans and Dierickx, 2004). This tension – between the "voice in the wilderness" (that no one hears) and "going native" (thereby losing the distinctive, critical perspective offered by sociology) – can be used productively: distance allows challenges to the common-sense of bioethics and closeness allows the analyses of social scientists to be incorporated into the work of bioethicists (De Vries et al., 2007).

The articles collected here focus on the place of trust in the quandaries and work of bioethics. It was our stranger's standpoint that led to the choice of this theme. We solicited articles on trust because we found it odd that bioethicists paid so little attention to an issue that is central to their work. From a sociological point of view, bioethics is a field born of *mis*trust. Although the paternity/maternity of bioethics remains in dispute – with claims and counter claims about who coined the term and who developed which of its key principles (Beauchamp, 2003; Campbell, 2000) – it is generally agreed that the field rose in response to either research or clinical abuses (or both). Those who place the origins of contemporary bioethics in the research scandals of the Nazi era and the exposés of harm to research

[1]This depends on whether one is a sociologist *in* bioethics (one who uses social science to answer bioethical questions) or a sociologist *of* bioethics (one who uses bioethics to answer sociological questions). See De Vries, 2004.

subjects in the US (Beecher, 1966) and the UK (Pappworth, 1967), see bioethicists as the rescuers and purifiers of medical research. In this scenario bioethics re-establishes trust in a flawed system. Those who see the origins of bioethics in the abuse of patients by hospitals and the purveyors of new and frightening medical technologies cast bioethicists as advocates of vulnerable patients against untrustworthy medical power. In both narratives, bioethics moves trust from one set of actors (researcher or physicians) to another (bioethicists or bioethics committees). Indeed, one could argue that the work of bioethics is nothing more or less than a process that formalizes trust and then moves it between actors in clinical and research settings.

This "outsider" observation about bioethics and trust informs an "insider" empirical bioethics that "seeks out what is good" and "understands the concrete conditions for achieving those [good] aims" (van der Scheer and Widdershoven, 2004, p. 78). There is much work to be done in this regard. There are philosophical disquisitions about trust (and autonomy, see O'Neill, 2002), as well as occasional articles about promoting trust in health care settings (Goold and Klipp, 2002), but a thoroughgoing sociology of the place of trust in bioethics has yet to be written. We need to know more about the cultural and structural sources of trust, about the varied manifestations of trust, about the effects of different ways of managing trust.

Consider, for example, the movement of trust in the oversight of research. Research ethics committees (RECs) have moved trust from the *person* of the researcher to a *process* administered by members chosen for their expertise and/or identity. Does this solve the problem of research abuse? In the end, RECs must trust researchers to do as they say they will do in the approved protocol – committee members cannot oversee every informed consent process and every interaction between researcher and subject. Furthermore, there is evidence that moving trust from the subject-researcher level to the REC-researcher level prompts more devious behavior as researchers seek to escape what they deem to be needless and cumbersome regulations (Keith-Spiegel and Koocher, 2005).

In their contribution, "Regulation and the social licence for medical research", Dixon-Woods and Ashcroft (2008) explore the place of RECs in the network of trust. Those who do medical research – many (most?) of whom are frustrated by the oversight of their work by research ethics committees – ask: "Is medical research over-regulated?" "Does the regulation of medical research successfully protect patients or promote ethical conduct?" But, as Dixon-Woods and Ashcroft explain, these questions miss the deeper point that research regulation is an effort to shift trust from the micro-level of researcher and subject to the larger level where subjects are asked to trust an oversight system that closely monitors the behavior of researchers. Using the work of sociologist C. Everett Hughes, these authors argue that the oft-criticized regulatory system actually serves to provide researchers with the "license and mandate" to do their work. In their words: "Regulation, often a focus of complaint by researchers, is thus critically important in allowing researchers to be admitted to the category of "medical research" and provides a moral warrant for their activities".

In an interesting piece of survey research, Kim and his colleagues (2008) explore "forms of trust" in clinical research. Their data show that research subjects and research ethics committee members have very different views of clinical trials. Subjects have an optimistic view of research based on trust in the research enterprise, while ethics committee members exhibit a "protective pessimism" distrusting the abilities of both the researcher (to convey objective information) and the research subject (to understand the information they are given). This article widens the lens of research ethics (to include both subjects and regulators) and challenges the idea that research subjects suffer from the "therapeutic misconception" (TM) – the tendency to see their participation in clinical research as

treatment. It may be that the "trust gap" between the subjects' and ethics committee members' views of clinical research is as much the product of committee members' pessimistic perceptions as it is the result of the optimism of research subjects.

Like the ethics committee members surveyed by Kim et al., the pharmaceutical companies that sponsor clinical trials also distrust researchers and subjects. Using data from her study of clinical trials in the US, Fisher (2008) shows how (dis)trust is built into the system of drug research. Fisher makes the strong sociological claim that "a focus on trust solely within the clinician-subject dyad is empirically deficient and ethically dangerous". She demonstrates that what seems an obsessive concern with the behavior of researchers and subjects on the part of drug companies is not surprising in a neo-liberal health care system where "physicians and human subjects participate in clinical trials for their own instrumental motives (i.e., financial gain for physicians and access to the medical establishment for subjects)". Lacking a sense of the common good, "socially-oriented incentives for involvement in clinical trials do not exist," and thus "pharmaceutical companies must develop structures that control the behavior of clinicians and human subjects".

In his contribution, "The politics and bioethics of regulatory trust: Case-studies of pharmaceuticals", Abraham (2008) looks at those who regulate the pharmaceutical industry. Using examples from the US and the UK Abraham distinguishes 'investigative' and 'acquiescent' norms of regulatory trust. He shows how the move from the former to the latter – abetted by the "capture" of regulatory systems by industry and the confluence of professional and industry interests – has resulted in more permissive standards that allow pharmaceuticals to go on the market with weaker evidence of therapeutic efficacy and greater risks to health.

Hallowell (2008) turns our focus to the clinic and an examination of the factors that promote and discourage trust in provider-patient relationships. Her data come from interviews with 49 women who used prophylactic surgery or ovarian screening to manage their risk of ovarian cancer. Hallowell observed that a patient's trust in her caregiver was closely associated with respect: women who felt that they were treated disrespectfully by their doctor were less likely to trust the information and the care provided by that doctor. In today's world trust has been personalised. This is not surprising: when a more paternalistic model of care prevailed, trust in physicians was dictated by structural factors (i.e., trust in medicine and the medical profession). The egalitarian, consumer-oriented approach to provider-patient relationships that prevails today shifts trust to the relational level. Along with O'Neill (2002), Hallowell argues that clinical relationships should be governed by a Kantian view of autonomy that "promotes respectful and trusting relationships, based on mutual obligations, or respect for persons, rather than on externally imposed rules".

Pinxten et al. (2008) review the many problems associated with using children in clinical trials. While the need for this type of research is indisputable, the problems associated with enrolling minors in research seem insurmountable: Under what conditions should this kind of research be done? Who should provide consent? At what age/level of maturity can a child provide consent/assent? With an eye on the regulations for clinical research in the EU, Pinxten and his colleagues propose a renewed focus on "trusting relationships" as a means to promote morally proper recruitment of, and consent from, children in clinical trials.

These studies in the sociology of trust, inspired by a view of bioethics from the outside, are useful for the work of bioethics. They offer bioethicists the opportunity to ask: how does our place in health care and the life sciences influence the trust that is essential for these systems to operate? How does our presence enhance, diminish, and reallocate trust? In bringing these

questions from the periphery to the centre of bioethics, sociology proves its value for the interdisciplinary work of this new field.

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