Data Sustainability as a Framework for Justice in Health Data
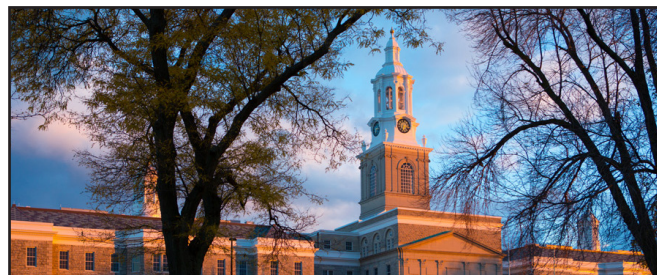
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Abstract:

Data is something with which we generally are familiar, we speak of it often, and seem to know to which sorts of things we refer, but its features both as a "brute object" and as a social object need to be better comprehended and more precisely defined before we develop a coherent framework for data "governance" Messy, inaccurate, or just plain wrong views of what data is and is not have resulted in haphazard approaches to it as an object of governance, and sometimes incoherent views among the general populace about their "rights" to data or their duties toward it. In this talk, we will examine some relevant features of data, compare and contrast it with other sorts of objects, and conclude with a precis of a new paradigm for data governance: data sustainability.

I have framed this discussion in terms of five different elements. One is discussing the positive claims about what data is. Another thread contrasts those with negative claims about what data is not. As well, I discuss what I call the data ecosystem as it exists, that is a descriptive part of the project, and then I will explain what data ecology is. That is a more prescriptive discussion. I conclude by setting out a research program, to frame our relationship with data differently ~ to implore us to consider data as being something like a natural resource like water or air, and to think about how it is we might relate to data if it were such a form of natural resource ~ if it were not capable of being owned or contained just as the water air is not really capable of that sort of control. How might we instead relate to a data ecology where the value of sustainability is included?

Biography:

David is an entrepreneur, author, philosopher, attorney, and educator whose recent research focuses on the nexus of science, technology, ethics, and public policy. He has been a tenured Associate Professor of Philosophy at the Delft University of Technology, Faculty of Technology, Policy, and Management in the Netherlands, Visiting Professor at UNAM, Instituto de Filosoficas and the Unidad Posgrado, Mexico, Director of Research and Strategic Initiatives at COMISION NACIONAL DE BIOETICA in Mexico, and Asesor de Rector at UAM Xochimilco. His is co-founder of EncrypGen, Inc. and BTblock Health

Publication of speakers:

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2. Koepsell, David. Who Owns You?: The Corporate Gold Rush to Patent Your Genes. John Wiley & Sons, 2009..

3. Koepsell, David. (2019). Blockchain, Wikis, and the Ideal Science Machine: With an Example From Genomics. Frontiers in Blockchain. 2. 25. 10.3389/fbloc.2019.00025.

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