Misha Angrist: Here is a Human Being: At the Dawn of Human Genomics
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Misha Angrist (Duke) presented perspectives from his forthcoming book *Here is a Human Being: At the Dawn of Human Genomics*. As one of the people whose entire genome has been sequenced and made public in genomic databases through the Personal Genome Project, Angrist has been personally involved in much of the politics and science of personal genomics. He traced a history of personal genomics, starting with the celebration of the Human Genome Project. Around 2004, people started to speak out loud about the potential future uses of genomics knowledge. Once there was a consensus haploid genome, it would become possible to start doing many more genomes. George Church (PGP) and Ryan Phelan (DNA Direct) started to frame genetic testing as a form of empowerment over one’s body and health. 2005 saw the Human Genographic Project and ClinENCODE, a clinical genomics project funded by the NHGRI. In 2006, Church argued in *Scientific American* that it was necessary to turn humans into a model organism to follow through on the promises of human genomics, proselytizing ‘genomes for all.’ Angrist suggested that 2007 and 2008 were the years in which the idea of DIY genomics really took off and the public finally had access to tools for sequencing and interpreting genomes. Part of the effort to get genomics into the hands of civilians was the need to circumvent institutional review boards. One element of the DIY effort was to provide access to knowledge with very little editorializing; for instance, SNPedia is an open source tool for interpreting one’s SNP results just links out to the scientific literature. In 2007 the first personal genomics companies appeared on the scene. The year 2007 also saw the public efforts by a clinical geneticist and father of a daughter with Marfan’s Syndrome Hugh Reinhoff draw attention to rare genetic diseases—a form of research politics Angrist called ‘very personal genomics.’ Angrist noted a common origin story for these early advocates of personal genomics in a frustration with NIH funding limitations, the challenges of getting SNPs into molecular diagnostic labs, and the lack of progress in getting genomics data to lay people. Correlated with these efforts was a shift in the mood of administrators about personal genomics, including positive editorials in major scientific journals and Francis Collins touting the potentials of consumer genomics in 2008. In 2009, a series of studies emerged about the early users of personal genomics which allayed some of the fears of its critics. Now, in 2010, the attention paid to personal genomics has exploded, including the plans to sell direct to consumer kits at drug stores, campaigns to end preventable genetic diseases through testing, the ruling against Myriad’s BRCA patents, and a paper in the Lancet advocating for incorporating personal genomics into clinical assessment.

In discussion, Angrist was asked why there appears to be only two models of the relationship between genetic data and medical care: doctors are supposed be gatekeepers, but data is also supposed to be public. He responded that PGP aims for full individual control over one’s own data, but the funding mechanisms and limited resources have made a sophisticated redaction mechanism out of reach. Furthermore,
it is perhaps impossible to scrub data out of one’s genome sequence without putting huge scars in the sequence.