The 70th anniversary of the Nuremberg Code was celebrated in 2017. The code is a set of principles intended to guide the conduct of research in the aftermath of the Nazi experiments during WWII, with the first principle reading, “The voluntary consent of the human subject is essential.” The year 2019 will be the 40th anniversary of the Belmont Report, drafted in the aftermath of the Tuskegee syphilis experiments to provide a foundation for ethics and regulations governing human subjects research. Yet, despite decades of experience, ethical analysis, and regulatory oversight, informed consent for research is commonly described as broken. In this discussion, we will discuss the current limitations of the consent form and process and the challenges to achieving informed decision-making in clinical research and clinical care. Several strategies to improve the form and process will be discussed.

For background reading before this discussion, please contact linda.carrlee@hsc.utah.edu

For those interested, Dr. Botkin will also be presenting the David Green Lectureship, “Biobanking Newborn Bloodspots: Henrietta Lacks Revisited” at Pediatric Grand Rounds the next morning, Thursday, February 21, 2019, 8am, Primary Children’s Hospital, 3rd floor Auditorium.