The use of residual newborn blood spots for research poses an interesting array of opportunities and dilemmas. In many countries where newborn screening is performed, these spots are obtained from virtually every newborn. They represent unusually complete population-based samples, which can be tested for genetic variants and a variety of metabolic and other markers. These samples, however, are quite limited in quantity, particularly when compared with immortalized cell lines or even with blood samples typically obtained from adults. Relatively little can be learned from the blood spots themselves beyond the distribution of a measured variable among a particular population of neonates. Very little phenotypic information is contained on most birth certificates, and typically little is directly known about the “history” of most newborns. The greatest value for research occurs when children’s blood spots can be linked with subsequent records of their lives regarding such matters as medical care and education.

Newborn screening typically is performed without parental permission, justified on the ground that routine testing is warranted to detect potentially treatable disorders. Parents rarely know about research using these blood spots. Consent, however, is typically required for most research. Should parental permission be required for this type of research? If so, how should it be obtained? Has too
much emphasis been placed on autonomy and voluntariness at the expense of solidarity and the public good of greater knowledge? Does the public’s decision to conduct this research provide a sufficient ethical foundation even in the absence of parental permission? Does the nature of the public’s decision matter? For example, does a bill enacted by the legislature confer greater legitimacy than a decision by an administrative agency? What sorts of oversight are needed, particularly in light of the need for stewardship of newborn blood spots, which are small and non-renewable? What level of risk is posed by this risk, and how can it be reduced? Should results relating to a particular child ever be shared with the parents?

These and other questions raise questions at the intersections of science, research ethics, and political theory. In this section, two authors from two countries that have different political and ethical histories will provide enlightening perspectives on these questions and the dilemmas that they present, which shed light both on research involving using residual newborn blood spots and the more pervasive questions raised by the use of DNA databanks.