Recent developments at the intersection of biological, information and communications technologies have opened the way to profound transformations in biomedical research and practice by eliciting and aggregating data from human bodies at scale and scope that were previously unimaginable. Such bodies of data form a critical infrastructure for developing a more precise and personalized medicine. Building such collections depends upon the consent of individuals to supply information and tissue from their bodies, even as the future uses and meaning of such information is necessarily uncertain.

These developments have elicited profound questions about—and new experiments in—architectures of governance. Increased access to these technologies has attracted new actors, engendered new uses, and elicited new modes of participation in research. Examples include disease advocacy driven research, crowd-sourced citizen science, and products like direct-to-consumer genetic testing. These new entrants bring different imaginations of rights and benefits, challenging traditional approaches to biomedical research and blurring distinctions between consumer, patient and research subject.

There is a need to rethink established regimes of governance. How will these developments affect the rights, roles and responsibilities of scientists, physicians, regulators, citizens, consumers, research participants, and patients? What opportunities—and obligations—exist for extending public participation in research to include a participatory role in governance? This workshop will examine contexts where existing architectures of ethical governance have been strained and challenged, and where forms of innovation and experimentation have begun to emerge. It will draw together an international group of leaders from the biomedical sciences, engineering, social sciences, humanities, industry and government.