

Piloting a Patient Data Use Agreement in the MassChallenge HealthTech Program

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As more health *and* health care goes digital, patients are navigating how to access and use their data in unprecedented ways. While the technology is moving quickly to meet patient needs, the legal aspects associated with individual data ownership are still developing. Through a partnership with MassChallenge, MITRE is piloting innovation in the form of a model “Patient Data Use Agreement” with several start-ups that aim to build their business and data offerings in ways that put patients in the digital health driver’s seat.

Through its standing [Bridging Innovation](#) Initiative, MITRE builds pathways that connect the government with the high-tech ecosystem to discover, accelerate, and deliver innovative solutions emerging from start-ups and other non-traditional sources. This past January, MITRE expanded this work to include a specific pilot approach with the [MassChallenge HealthTech](#) program in Boston. The pilot, led by Mary Quilty, Bridging Innovation Lead for MITRE’s engagement in MassChallenge HealthTech, brings MITRE research to start-ups and aims to establish an integrated, programmatic partnership by which additional MITRE research initiatives can enter a virtuous cycle with start-ups and the broader healthtech ecosystem to drive speed to impact.

A key strength of the pilot involves leveraging a long-standing internal MITRE Innovation Program that provides seed funding to MITRE researchers tackling challenges facing government and industry. One researcher, Katherine Mikk, JD, elected to leverage the pilot to gain real-time, real-world user feedback on her model Patient Data Use Agreement, a templated legal document that can simplify the complex issue of patient data ownership for entities exploring the collection and management of data at the patient level.

Through the pilot, the model Patient Data Use Agreement is being systematically adopted by several vetted and matched startups from the MassChallenge HealthTech 2020 cohort committed to developing best-in-class approaches to supporting the role of patients in owning, accessing, using, sharing and moving their data in ways that drive patient-empowerment. The pilot approach is enabling Mikk to learn ‘from the field’ how best to evolve the model Patient Data Use Agreement so it can be more accessible, customizable, and ultimately leveraged by a wide range of organizations as patients increase their ask to own their health and healthcare data.

“Many start-ups we evaluated have both a business and a mission focus. They were drawn to the model Patient Data Use Agreement given its ability to provide a structured, comprehensive, and simpler way to bring the needs of patients to the forefront of their offerings, and participation in the pilot because it provides multidisciplinary expertise throughout the adoption process” shared Quilty.

The model Patient Data Use Agreement is an open source resource and can be found [here](#). If you are interested in learning more, please contact Mary Quilty at mary@mitre.org to start a dialogue.