# Solving the Problems of Data Bias and Access through a Global Medical Data Donation Program

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## Abstract

Statement of the Problem: Access to high-quality, representative, and unbiased medical data is an enormous and urgent roadblock to progress in medical science. Machine Learning and AI Algorithms are only effective and reliable if the datasets they use to train can be trusted, and while these technologies are already being used successfully in medical research, their true potential is being limited by the lack of data to run them on. Ethically sourcing the data, navigating legislation, privacy concerns, and educating patients regarding the importance of their data pose additional and not-insignificant challenges. Medical data is currently fragmented, and locked away in hospitals with no easy way of accessing it for researchers, particularly smaller startups without the financial means of big tech. For hospitals, the storage of data represents both a legal obligation as well as a financial burden. Depending on the country of residence of a patient, their medical data is either forcibly requisitioned by the government, or bought and sold on an open market - in both cases the consent of the patient is not sought and often it is done without even the patient's knowledge.

Proposed Solution: An international coalition of organisations representing patients, healthcare providers, and research institutions as well as the EU-funded startup Data Lake have created a solution, by launching the first global medical data donation program. Much like giving blood, patients will be given the ability to give and revoke legal consent to the use of their medical data. Once retrieved from their healthcare facility or service provider, data will be stringently anonymised in order to protect patient privacy. To remove the need for trust in such a critical system, patients' consents, consent revocations, and all operations on their data will be written to a public, immutable blockchain. To incentivise participation in the system (beyond the psychology of altruism that drives the success of blood and organ donation schemes), all stakeholders in the medical data ecosystem will share the rewards of data purchases, including donors themselves.

## Biography

The Dinidh O'Brien is a communications executive and startup consultant with more than a decade of experience promoting and integrating emerging technologies across the private and public sectors, including work on projects at the EU level. He is the Global Head of PR and Marketing for Data Lake, an EU-funded startup that is creating the technology and framework for the world's first international medical data donation system. This revolutionary programme is based on the pillars of patient consent, privacy, and data ownership and will provide large, anonymised datasets to researchers for research and development purposes, particularly in the AI and ML fields.