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PROTECTING GENETIC PRIVACY IN FUTURE SPACE EXPLORATION

Abstract

The future of space exploration will certainly include human missions and the creation of permanent settlements in outer space. Given the hostility of the space environment and the hazardous effects that microgravity has on human health, it is crucial to understand the reactions of our body to such extreme conditions. Long-term missions have been limited, leading to a lack of sufficient data to investigate the medical risks related to space and microgravity environment. One of the longest missions to date has been part of a recent NASA study, which involved two twin astronauts: Scott and Mark Kelly. The first twin joined the crew of the International Space Station, while the latter stayed on Earth. The study aimed to understand better the effects of the space environment on the human body, as this unique case was a valuable opportunity for NASA's Human Research Program to investigate the different behavior of the same genetic structures in space and on Earth. In the Twins Study, as in previous human missions and investigations, concerns regarding the collection of astronauts' genetic material for research or occupational surveillance purposes were highly debated, particularly regarding privacy protection and the identification of collected data. This work analyzes the current legal status of research conducted on astronauts' genetic information, introducing the different approaches proposed by space agencies around the globe. ESA and NASA policies will be analyzed in more detail. It will follow a comparative study on genetic data collection and privacy regulation at a national, regional and international level, to identify possible gaps and convergences in the different policies and provide a set of recommendations to the space agencies. The investigation will further present the advantages that pharmacogenetics could bring to astronauts' health, allowing personalized treatments, and minimizing adverse drug reactions. The study concludes with the necessity to find a balance between the protections of astronauts' privacy rights and the development of researches on humans' reactions to the space environment. It recommends the creation of a closed blockchain platform, that would constitute encoded digital storage of genetic data, accessible only under predetermined conditions; it ultimately investigates its weaknesses and possible threats.