

Lo spazio europeo dei dati sanitari e il buon cittadino europeo: fare di virtù necessità?

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The European Health Data Space and the Good European Citizen: Making a Virtue Necessity?

Abstract: The European Health Data Space (EDHS) is presented as strengthening EU citizens' (digital) rights, in particular as it aims at empowering them to control their own health data whilst at the same time facilitating their secondary use. However, the Regulation proposal issued in 2022, later amended and recently adopted raised various critiques, in particular as it poses serious concerns regarding the protection of fundamental rights as well as some fundamental democratic principles and values. The text of the Regulation presents many issues, starting from a patent contradiction between its two main declared aims, namely that of empowering citizens' rights over their health data and favoring the secondary use of health data for the benefits of society, as the latter risks to be done at the expenses of the first. Moreover, several regulation provisions seem to be in contradiction with EU primary and secondary legislation, as well as with some relevant body of soft law. Moreover, the Regulation does not seem to be fully aligned with the concept of "data altruism" (which it aims at favoring), given that it foresees the possibility of overriding EU citizens' choices related to health data sharing even against their explicit will (opt-out) by providing alternative grounds of legitimizing health data processing in the name of public good. This article will consider these concerns with a focus on their impact on EU (Digital) Citizenship, in particular considering that 2025 will be the European Year of Digital Citizenship Education.

Keywords: European Health Data Space, European citizenship, Digital citizenship, Fundamental rights, Data protection.

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