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European Health Data Space a compromise between healthcare needs and protecting data

The European Health Data Space agreed today by the EU institutions is a step forward to improve healthcare. However, the institutions should have given more choice to people to decide for themselves who their data is shared with, and for what purpose.

The data space will allow a medical practitioner to access the health data of a patient from another EU country who is wheeled into the emergency room unconscious. It will allow better treatment by taking into consideration the patient's history, past diagnoses or current medication. The health data space will also enable researchers and public health authorities to access this data in an anonymised or pseudonymised format to develop better treatments.

However, BEUC regrets that the concerns consumers express in sharing their health data, which is clear from a [survey](#) published last year, are not reflected sufficiently in the legislation. People should be given more direct choice over with whom and for what purpose their data gets shared. Consumers will also be unable to make use of collective redress tools if a company illegally accesses their data, which is a major barrier to get compensation for when people's health data has been abused.

Monique Goyens, Director General of the European Consumer Organisation (BEUC), said: "The Health Data Space is a project with noble intentions which will improve healthcare and outcomes for people. When you go abroad, it makes sense that doctors and nurses have access to your file to know what medication you take or what your past diagnoses are. But it is a real shame that the EU institutions did not pay more attention to consumers' wishes to stay in control of their data because that is the way to build trust in the project. The idea that consumers may not be able to say no to sharing their data is not reassuring and will seriously impact their trust in the EHDS system."