Préférences de la population générale adulte pour le partage électronique de données de santé en France – Un best-worst scaling de type 2

Gabin MORILLON, Marlène GUILLON

Abstract

Electronic health record platforms promise better care coordination and new uses of health data but expose individuals to privacy risks, so that their governance involves a trade-off between collective benefits and individual control. How the public values the terms of this trade-off has rarely been measured for an existing national platform. We elicited the preferences of the French general public for the governance of Mon Espace Santé, the national platform, using a case-2 best-worst scaling survey of ten attributes and 42 levels, administered online to a quota sample of 1,498 adults. We estimated mixed and latent class logit models and related class membership to individual characteristics with a bias-adjusted three-step method. Storage location was by far the most important attribute: storage in France was among the most valued levels, and storage in the United States the most rejected. Respondents also favored being informed before documents are uploaded and at every access, use restricted to care, and broad access by health professionals, while rejecting non-certified private hosting, private research, and private insurers. Two main classes emerged: a care-oriented class (44%) valuing broad access by professionals, and a control-oriented class (30%) valuing consent, notification, and access restricted to the general practitioner. A third class (27%) mainly reflected low engagement with the task. Class membership was associated more with perceived benefits and risks of data sharing than with sociodemographic characteristics. Mon Espace Santé is aligned with these preferences on storage and use, but diverges on account creation, notification, and retention.