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VIII Annual Symposium on Biomedicine, Ethics and Society: "Rethinking Informed Consent: The limits of autonomy"

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Voice beyond choice: informed consent as a hindrance for normative learning?

The introduction of predictive genetic tests in health care has stimulated many public debates about the ethical dilemmas of these tests. However, these debates often result in an appeal to the individual autonomous choice of people. While referring to the autonomous choice of people seems to be the only and inevitable answer to ethical issues in a plural society, we think this is an unsatisfying solution empirically and conceptually. For, from our fieldwork and interviews with professionals, patients and families that are involved in genetic testing for cardiovascular diseases it appeared that the idea of autonomous choice does no justice to the actual processes they go through and does not protect to them for difficulties. Moreover, one might ask whether the idea of protecting individuals should be the primary goal of ethics.

In our paper we will explore the fruitfulness of the work of Alfred Hirschman and especially the concepts exit and voice to argue that the dominance of autonomous choice as a strategy to deal with new medical technologies is a hindrance to public learning. While exit implies saying no by silently walking away, voice implies experimenting and deliberating the norms that are at stake. According to Hirschman public learning about complex normative goods like genetic tests requires voice. So besides organizing informed consent – generating a silent yes or no – we should organize and institutionalize ways to invite people to share normative experiences to learn about the different ways to live a good life with genetic tests.