

Publication

Autonomy and Fear of Synthetic Biology: How Can Patients' Autonomy Be Enhanced in the Field of Synthetic Biology? A Qualitative Study with Stable Patients

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We analyzed stable patients' views regarding synthetic biology in general, the medical application of synthetic biology, and their potential participation in trials of synthetic biology in particular. The aim of the study was to find out whether patients' views and preferences change after receiving more detailed information about synthetic biology and its clinical applications. The qualitative study was carried out with a purposive sample of 36 stable patients, who suffered from diabetes or gout. Interviews were transcribed verbatim, translated and fully anonymized. Thematic analysis was applied in order to examine stable patients' attitudes towards synthetic biology, its medical application, and their participation in trials. When patients were asked about synthetic biology in general, most of them were anxious that something uncontrollable could be created. After a concrete example of possible future treatment options, patients started to see synthetic biology in a more positive way. Our study constitutes an important first empirical insight into stable patients' views on synthetic biology and into the kind of fears triggered by the term "synthetic biology." Our results show that clear and concrete information can change patients' initial negative feelings towards synthetic biology. Information should thus be transmitted with great accuracy and transparency in order to reduce irrational fears of patients and to minimize the risk that researchers present facts too positively for the purposes of persuading patients to participate in clinical trials. Potential participants need to be adequately informed in order to be able to autonomously decide whether to participate in human subject research involving synthetic biology.

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