

## Publication

The full spectrum of ethical issues in pediatric genome-wide sequencing: a systematic qualitative review.

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The use of genome-wide sequencing in pediatric medicine and research is growing exponentially. While this has many potential benefits, the normative and empirical literature has highlighted various ethical issues. There have not been, however, any systematic reviews of these issues. The aim of this systematic review is to determine systematically the spectrum of ethical issues that is raised for stakeholders in in pediatric genome-wide sequencing.; A systematic review in PubMed and Google Books (publications in English or German between 2004 and 2021) was conducted. Further references were identified via reference screening. Data were analyzed and synthesized using qualitative content analysis. Ethical issues were defined as arising when a relevant normative principle is not adequately considered or when two principles come into conflict.; Our literature search retrieved 3175 publications of which 143 were included in the analysis. Together these mentioned 106 ethical issues in pediatric genome-wide sequencing, categorized into five themes along the pediatric genome-wide sequencing lifecycle. Most ethical issues identified in relation to genome-wide sequencing typically reflect ethical issues that arise in general genetic testing, but they are often amplified by the increased quantity of data obtained, and associated uncertainties. The most frequently discussed ethical aspects concern the issue of unsolicited findings.; Concentration of the debate on unsolicited findings risks overlooking other ethical challenges. An overarching difficulty presents the terminological confusion: both with regard to both the test procedure/ the scope of analysis, as well as with the topic of unsolicited findings. It is important that the genetics and ethics communities together with other medical professions involved work jointly on specific case related guidelines to grant the maximum benefit for the care of the children, while preventing patient harm and disproportionate overload of clinicians and the healthcare system by the wealth of available options and economic incentives to increase testing.

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