

NUFFIELD COUNCIL ON BIOETHICS

Submission to Science and Technology Committee's 'My Science' inquiry

1. The Nuffield Council on Bioethics is an independent organisation that examines and reports on ethical issues arising from developments in biological and medical research that concern the public interest.
2. We suggest 'commercial genomics' as a topic that requires scrutiny by the Science and Technology Committee. The Committee has recently examined genomics in the NHS, but the private genomic testing sector is booming, largely unchecked. Commercial genomics companies in the UK and abroad are offering or developing tests that promise insights across the life course - from preconception, prenatal and newborn screening, to whole genome sequencing of adults.
3. The issues that require further examination include:
 - how to ensure that commercial testing companies meet high standards of service and care, with regard to e.g. consent processes, test accuracy, interpretation of results, and pre- and post-test counselling;
 - the impact on NHS staff and services of more people seeking private genetic testing services;
 - the permissive regulation and oversight of genetic tests and testing services;
 - whether commercial companies have adequate measures in place for storing and sharing sensitive genetic data and samples data; and
 - whether commercial companies are abiding by UK advertising standards.

Contact

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