The duty of care in the genomics area

Rights, responsibilities and legal duties

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The Duty of Care in the Genomics Era: Rights, Responsibilities and Legal Duties

1. The central obligation of professionals working in genomics is to properly consider the state of the art, the rights and interests of patients and their relatives, and the impact on society when developing policies. This thesis

2. Informed consent plays an important role as a starting point in addressing challenges, but at present cannot, and should not, guide all practice. This thesis

3. Multiple approaches to recontacting patients, reporting VUS or discussing secondary findings are currently within the scope of reasonable practice, but policies are unreasonable if they rule out any action to benefit or rescue individuals under any circumstances. This thesis

4. A legal duty may be imposed if professionals are able to provide individuals with information which could help them avoid serious harm without too much effort. This thesis

5. There is a duty to consider warning genetic relatives of actionable risks without patient consent where HCPs are in possession of definite, reliable and critical information relating to a family member known to HCPs. This thesis

6. The courts are unlikely to diverge significantly from professional consensus on matters which have been discussed and agreed by professionals. This thesis

7. Maintaining conceptual clarity as far as possible between research and healthcare is still the best means of assisting patients and professionals (and courts) to have accurate expectations about professional responsibilities.

8. The labelling of an activity as ‘research’ will not preclude responsibility to participants or liability.

9. There is nothing exceptional about genomic medicine or genomic research but genomic information is special.

10. Real knowledge is to know the extent of one’s ignorance. Confucius

11. Little strokes fell great oaks. Benjamin Franklin