WTDTP Projects for September 2023

Project Reference: T4/50

Project Title: **Examining the legal, ethical and social implications of whole genome sequencing at birth**

Theme(s): Theme 4: Ethical, legal and social implications of genomics and genomic epidemiology studies

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Project Summary: Developments in genomic testing mean that it is now possible to conduct whole genome sequencing of newborn infants. In November 2019 the UK Health Secretary announced his ambition for all infants to receive such screening and the Newborn Genomes Programme is currently exploring the benefits, challenges, and practicalities of this. Whilst population-wide newborn genome sequencing is not currently practicable, it is likely to become a reality within the foreseeable future. Sequencing offers a number of potential benefits to the infants, their families and the wider population, but concerns have been raised, including in relation to the obtaining and storage of personal data before the child has capacity to provide informed consent, the reliance upon parental consent in circumstances where parents may underestimate risks, confidentiality, privacy and the possible potential uses of data for forensic and commercial purposes, and whether such testing is always in the best interests of the child. This PhD study will review the literature in relation to newborn genetic sequencing, identifying, critically exploring the social, legal and ethical issues in relation to such programmes.