A hospital is under investigation by the Data Protection Commissioner (‘DPC’) over the DNA it is keeping on millions of newborns as part of its operation of the National Newborn Screening Programme.

The Programme was established in 1966 to screen all newborn infants for Phenylketonuria (‘PKU’). It is facilitated by Children’s University Hospital in Dublin on behalf of the Health Service Executive and the Department of Health and Children.

The DPC has now discovered that the Hospital has been indefinitely retaining the blood samples, reportedly gathering over 1.5 million blood samples from ‘heel prick tests’ on newborns which are sent to it for screening. The blood samples are being stored at room temperature on cards with information including the baby’s name, address, date of birth, hospital of birth and test result.

In addition to the data retention, the Hospital has allowed scientists from a university and other hospitals to access the Newborn Screening Cards for research purposes. The access was done on an anonymous basis but without the prior consent of parents.

The DPC is now engaged in urgent discussions with the Hospital and the government departments to ensure that the Programme complies with data protection legislation. He said “clearly it is a matter of significant concern to us that holding data of this nature containing sensitive health details of such a significant portion of the population appears to have operated without taking account of data protection requirements. “The issue of the justification for the holding of the blood samples for any period beyond that which is necessary to perform the initial...”

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