

# Data Protection Ireland

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## Headlines:

- Hawkes says global standards for internet privacy a must, p.14
- DPC recommends diverse range of measures, p.15
- Working Party declares Israel and Andorra 'adequate', p.16

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## Screening programme under 'urgent' investigation

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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## Ireland establishes first ever DNA database

The government has published a new Bill which, when in force, will establish the first ever national DNA database in Ireland.

The new Criminal Justice (Forensic Evidence and DNA Database System) Bill 2010 is the government's implementation of the recommendation of the Law Reform Commission in October 2005 that a DNA database be established with two main functions: (i) criminal investi-

gations and (ii) identification of persons.

When enacted, the Bill will require all individuals arrested for serious offences to provide DNA samples. Profiles generated from the samples will be placed on the database operated by the Forensic Science Laboratory which will carry out the analysis and communicate the results to the Gardaí.

Amendments to the Bill, such as the inclusion of specified retention periods for data, were made during the drafting stage to reflect the serious privacy concerns that the establishment of the database create. The Bill is also said to reflect the decision of the European Court of Human Rights in *S and Marper v UK* which requires shorter retention periods for samples (as opposed to profiles) and

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