



**AN BILLE CHUN CÁRTAÍ SCAGTHÁSTÁLA NAÍONÁN
NUABHEIRTHE A CHOINNEÁIL, 2013
RETENTION OF NEWBORN SCREENING CARDS BILL 2013**

*Mar a tionscnaíodh
As initiated*

ARRANGEMENT OF SECTIONS

Section

1. Definitions.
 2. Amendment of section 2 of the Principal Act.
 3. Amendment of section 2A of the Principal Act.
 4. Short title and commencement.
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ACTS REFERRED TO

Data Protection Act 1988
Data Protection Act 2003

1988, No. 25
2003, No. 6



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BILL

5

entitled

AN ACT, IN THE PUBLIC INTEREST, TO AMEND THE
DATA PROTECTION ACT 1988, AS AMENDED BY THE
DATA PROTECTION ACT 2003, TO PROVIDE FOR THE
RETENTION OF NEWBORN SCREENING CARDS, AND
10 CERTAIN RELATED MATTERS,

WHEREAS Article 8(1) of the Charter of Fundamental Rights
of the European Union provides that everyone has the right to the
protection of personal data concerning him or her;

AND WHEREAS Article 8(2) of the Charter of Fundamental
15 Rights of the European Union provides that such data must be processed fairly for specified purposes and on the basis of the consent of the person concerned or some other legitimate basis laid down by law;

AND WHEREAS everyone has the right of access to data which
20 has been collected concerning him or her, and the right to have it rectified;

AND WHEREAS the National Newborn Bloodspot Screening Programme is of vital national importance to the health of the Nation;

25 AND WHEREAS the retention of data contained on Newborn Screening Cards prepared as part of the National Newborn Bloodspot Screening Programme is of vital national importance to the health of the Nation and consequently the retention of such information is on a legitimate basis—

30 BE IT THEREFORE ENACTED BY THE OIREACHTAS AS FOLLOWS:

1.—In this Act, except where the context otherwise requires— Definitions.

“Principal Act” means the Data Protection Act 1988, as amended by the Data Protection Act 2003;

“National Newborn Bloodspot Screening Programme” means the programme of screening newborn children for certain genetic medical conditions soon after birth which commenced in 1966;

“Newborn Screening Cards” means the documents upon which the screening of newborn children for certain genetic medical conditions soon after birth are recorded. 5

Amendment of
section 2 of the
Principal Act.

2.—Section 2(1) of the Principal Act is amended by the insertion of the following new paragraph after paragraph (d):

“(e) Nothing contained in paragraph (c) shall operate to prohibit a data controller which is a health agency which holds information that was collected as part of the National Newborn Bloodspot Screening Programme which commenced in 1966 and which is recorded on a Newborn Screening Card which was collected for one or more specified, explicit and legitimate purposes, from retaining or using that information for other permitted purposes, to be specified by Regulation of the Minister for Health, where the use of the information for that other purpose is necessary to prevent or lessen a serious and/or imminent threat to (i) public health or public safety; or (ii) the life or health of the individual concerned or another individual.”. 10 15 20

Amendment of
section 2A of the
Principal Act.

3.—Section 2A is amended by the insertion of a new subsection after subsection (2):

“(3) Nothing contained in this section shall operate to prohibit a data controller which is a health agency which holds information that was collected as part of the National Newborn Bloodspot Screening Programme which commenced in 1966 and which is recorded on a Newborn Screening Card which was collected for one or more specified, explicit and legitimate purposes, from retaining or using that information for other permitted purposes, which are specified by Regulation made by the Minister for Health under section 2, where the use of the information for that other purpose is necessary to prevent or lessen a serious and/or imminent threat to (i) public health or public safety; or (ii) the life or health of the individual concerned or another individual.”. 25 30 35

Short title and
commencement.

4.—(1) This Act may be cited as the Retention of Newborn Screening Cards Act 2013.

(2) This Act shall come into operation immediately after its enactment. 40