

PRESS RELEASE

GPBuddy.ie asserts that the HSE's plan to destroy one million "Guthrie Cards" is based on unsound legal advice

13 March 2013

Background:

The various Health Boards and their successor, the HSE, have routinely collected medical information in the form of a heel-prick blood test on every infant born in the State since 1966. These Newborn Screening Card blood samples, or "Guthrie Cards", still survive for approximately one million infants born in Ireland between 1984 and 2002¹. The HSE acts as custodian of this information.

The HSE has announced that it has received legal advice indicating that the retention by the State of the Newborn Screening Card blood samples is contrary to EU and Irish Data Protection legislation, in instances where an infant (through a parent) has not explicitly consented to their retention. Prior to 2002, parental consent for the retention of this medical information was not routinely acquired.

Following a policy review, the HSE has announced that all Newborn Screen Card blood samples from prior to 2002 which are still in existence will be destroyed, where the retrospective consent of an individual to their retention is not forthcoming by 31 March 2013.

Legal Position of GPBuddy.ie:

Dr Darach Ó Ciardha, co-founder of *GPBuddy.ie*, Ireland's leading online platform for GP and Healthcare Professionals, maintains that legal advice received by the company contradicts the position adopted by the HSE. This is because *GPBuddy.ie*'s legal advice takes into account the nature of the information contained in the Newborn Screening Card blood samples and their potential to assist the Irish population in the genetic diagnosis of certain diseases.

GPBuddy.ie is therefore calling on the Data Protection Commissioner, in the first instance, to seek a judicial review of the HSE's decision before the High Court, on behalf of the one million citizens whose heel-prick blood test information still survives.

Legal Advice Explained:

According to Dr Darach Ó Ciardha of *GPBuddy.ie*:

"Whilst it is true that EU and Irish law prohibit the processing of personal data concerning a person's health without the consent of that individual², we have been advised that there exists an exemption to this under EU law where the processing of such information is required "for the purposes of preventive medicine, medical diagnosis, the provision of care or

¹ According to the HSE, all Guthrie Cards dating between 1966 and 1984 were unintentionally destroyed by water damage.

² Article 8.1 of Directive 95/46/EC of the European Parliament and the Council of 24 October 1995. Directive 95/46/EC was adopted to harmonise national provisions on protection of individuals in processing and free movement of personal data. The Directive has been implemented in all EU countries, including in Ireland under the Data Protection (Amendment) Act 2003.

treatment, and where that data is processed by a health professional subject under national law ³”.

Dr Ó Ciardha believes that the information contained on the Newborn Screening Card blood samples complies with this exemption, but notes that in transposing EU rules in this area into Irish law ⁴; the Government failed to take note of this preventative medicine exemption.

Various other medical professional bodies, including the Irish Heart Foundation, which has mounted an online campaign against the HSE's decision⁵, have also called for the retention of the Newborn Screening Card blood samples on medical grounds. The IHF's Chief Executive Barry Dempsey has pointed out that:

*"The crucial issue of genetic diagnosis was not addressed in the [HSE] policy review ... the information contained on the cards could save the lives of extended family members of more than 1,000 young victims of Sudden Cardiac Death."*⁶

Private citizens may also seek leave from the High Court for a judicial review of the HSE's decision on the basis of the HSE's inadequate regard to the preventative medicine exemption under EU law. It is an established tenet of EU law that where Irish legislation is defective in its implementation of an EU law, that the High Court must interpret such legislation in conformity with the EU Directive upon which it is based.

About GPBuddy.ie:

GPBuddy.ie is the most complete online medical directory built by GPs for Irish healthcare professionals. With over 2,100 of Ireland's GPs registered (over 80% of GPs nationwide) and at least 1,000 GPs using the site at least once per month, *GPBuddy.ie* is widely recognised by Irish GPs as the powerful medical directory in everyday clinical practice.

For additional information contact:

Dr Darach Ó Ciardha

GP and Director of GPBuddy.ie

Tel: (087) 987 2127

ENDS

³ Article 8.3 of Directive 95/46/EC. The Directive is available on the website of the Office of the Data Protection Commissioner here: <https://www.dataprotection.ie/viewdoc.asp?DocID=89>

⁴ The Data Protection (Amendment) Act, 2003 transposes Directive 95/46/EC into Irish law. The Act is available here: <https://www.dataprotection.ie/documents/legal/Act2003.pdf>

⁵ IHF online campaign: stopthedestructionnow.com

⁶ Source: <http://www.rte.ie/news/2013/0312/376284-ihf-in-call-for-heel-prick-tests-to-be-saved/>

Relevant legal provisions⁷⁸

EU Law:

Directive 95/46/EC - Article 8:

1. Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life.

2. Paragraph 1 shall not apply where:

(a) the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject's giving his consent; or

[...]

3. Paragraph 1 shall not apply **where processing of the data is required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of health-care services**, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.

Irish Law:

Data Protection (Amendment) Act, 2003 - Section 2B:

2B.—(1) Sensitive personal data shall not be processed by a data controller unless:

[...]

(viii) the processing is necessary for medical purposes and is undertaken by—

(I) a health professional, or

(II) a person who in the circumstances owes a duty of confidentiality to the data subject that is equivalent to that which would exist if that person were a health professional

⁷ Source: <https://www.dataprotection.ie/viewdoc.asp?m=&fn=/documents/legal/6aii-2.htm#8>

⁸ Source: <https://www.dataprotection.ie/documents/legal/Act2003.pdf>