

Freedom of Information Act 2000 – Reference Fol/14/399
Infant Screening

Request details

The subject of interest is the heel prick test (guthrie card). please answer the following:

- (1) from which date did your centre first start testing?
- (2) from which date did your centre first start storing the cards?
- (3) approximately how many cards do you currently hold in storage?
- (4) what are the purposes of storing cards once they have been tested? is research or further testing conducted on the cards and does any of the generic information pertained on the cards get used?
- (5) are there any instances where use of the stored cards lead to families being contacted?
- (6) do you have a policy for destruction of the cards?
- (7) have any cards been destroyed? if so, who requested this?
- (8) have any cards or their information/genetic material been released to any government agency, police, coroners or other party? if so, who may order a release of such information.
- (9) what generic information is available on each card?
- (10) what information do you store electronically from these cards?

Response

- (1) Testing for PKU commenced in Wales in 1970
- (2) Cards are stored for a minimum period of 5 years. We currently hold 15 years worth of cards
- (3) There are currently 550,000 cards held in storage.
- (4) The parent information leaflet explains the purposes of storing cards once they have been tested. The relevant section is included below and the link to the leaflet is
http://www.newbornbloodspotscreening.wales.nhs.uk/sitesplus/documents/1008/76996_BloodspotInfoParents_ENG_WEB.pdf

After screening, the section of the bloodspot card that has the written details of the baby is separated and destroyed. The section with the bloodspots is identified by a barcode number unique to both the card and the baby. This section will be stored securely for at least five years and may be used:

- to check the result
- to carry out other tests recommended by the doctor

- to improve the screening programme
- for research to help improve the health of babies and their families in the UK

This research will not identify the baby, and the parent(s) will not be contacted. There are strict laws that govern the use of the bloodspots and legally we have to keep to these. In the future, researchers may want to invite the parent or their child to take part in research that has been agreed by the Screening Division of Public Health Wales. This will only be for research projects that have been approved by a Medical Research Ethics Committee and the researchers will need to get the parent's permission to be involved. If the parent/ parents do not want to be invited to take part in research, they may let their midwife know and this information will be recorded on the bloodspot card.

(5) There have been no instances where this has happened.

(6) Yes

(7) To date the laboratory has received no request to destroy cards.

(8) The Laboratory conforms to UK standards see
<http://newbornbloodspot.screening.nhs.uk/standards>

(9) The information requested on the newborn bloodspot card can be viewed on the following link which is the guidance for completion of the card by health professionals.

http://www.newbornbloodspotscreening.wales.nhs.uk/sitesplus/documents/1008/77012%2003_Guidance_Notes_Completion_A5_4pp_web.pdf

(10) The baby's screening test results and demographics are stored electronically.