

Privacy Information

Details of Barts Health NHS Trust Privacy/Data Protection policy can be found at:-

<https://bartshealth.nhs.uk/privacy>

Eloise Patterson Project: Retinoblastoma gene mutations and risk of second primary tumours.

1. Introduction

The Retinoblastoma Genetic Screening Unit (RGSU) at the Royal London Hospital is carrying out a research study to investigate any link between the different types of genetic changes on the retinoblastoma (Rb) gene and the development of other kinds of cancer later in life. Previous studies have shown that people with heritable, genetic retinoblastoma (the type where other family members may be affected) have a greater chance of developing certain other cancers. This study aims to investigate whether certain types of mutation predispose 'genetic' patients to specific types of subsequent cancer, and whether there are differences in the overall risk of a further cancer depending on the specific type of mutation. We hope that this will give doctors more information when working out the chances of other cancers occurring. This could lead to earlier detection and treatment of such cancers.

2. Personal data that we collect about you

To carry out this study we need to use identifying information about patients with Rb - such as name, birthdate and NHS number.

3. How we use your personal data

This will let us match information about a person's Rb gene change to information on any later cancers that they may have had.

4. Who we share your personal data with

Personal data already held within the RGSU will be sent to the National Cancer Registration and Analysis Service (part of Public Health England) to allow them to identify any subsequent cancers which may have occurred. Information on these cancers will then be returned to the RGSU and linked to information about the type of Rb gene mutation present. This work will be done by RGSU researchers within the RGSU office at the Royal London Hospital.

Ethical approval has been given for this study, but because we will be using data going back over many years we cannot get individual consent from everyone whose data may be involved.



5. Lawful basis for processing

Data Protection Legislation requires that we meet certain conditions before we are allowed to use your data in the manner described in this notice, including having a "lawful basis" for the processing. The basis for processing will be as follows:

- Public task. The processing of your personal data may be necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in us. For special category personal data, the following lawful bases for processing will be used:
- Article 9(2)(j) of the GDPR: processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

6. International transfers

We do not transfer your personal data outside the European Economic Area (EEA).

7. Information security

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. We have established procedures to deal with any suspected personal data breach and will notify any applicable regulator of a breach where we are legally required to do so.

8. Data retention

Personal data will be used for a short time; once the match is made then the personal data will be removed. It will then be impossible to identify the patients in the study.

9. Your rights

Under certain circumstances, you may have the following rights under data protection legislation in relation to your personal data:

- Right to request access to your personal data;
- Right to request correction of your personal data
- Right to request erasure of your personal data;
- Right to object to processing of your personal data;
- Right to request restriction of the processing your personal data;
- Right to request the transfer of your personal data; and
- Right to withdraw consent.

If you wish to exercise any of these rights, please contact the Data Protection Officer (available via the link at the top of this document).

10. Contacting the Retinoblastoma Genetic Screening unit

Potential participants can request that their data not be used for this work by contacting Dr Zerrin Onadim (Head of Retinoblastoma Genetic Screening Unit) on 020 3246 0265, or by e-mailing z.onadim@nhs.net. The patient will not then be included in this study.

If any potential participant would like to talk about heritable Rb and / or second cancers, they can contact Dr Elisabeth Rosser (020 7762 6856 / Elisabeth.Rosser@gosh.nhs.uk) at Great Ormond Street Hospital. They could also contact a support worker at the Childhood Eye Cancer Trust: Lesley Geen (020 7377 5578 / lesley.geen@chect.org.uk) or Julia Morris (0121 708 0583 / julia.morris@chect.org.uk).

This study is being funded by the Greendale Trust and is supported by the Childhood Eye Cancer Trust (CHECT).

11. Complaints

If you wish to complain about our use of personal data, please send an email with the details of your complaint to the Data Protection Officer so that we can look into the issue and respond to you. You also have the right to lodge a complaint with the Information Commissioner's Office (ICO) (the UK data protection regulator). For further information on your rights and how to complain to the ICO, please refer to the ICO website.