**FHQS Consent and Privacy Information**

**Why do we need this data?**

Up to 1 in 2 people will get cancer in their lifetime. Most cancers happen when people get older, and are not due to anything running in the family. However, sometimes we see more cancer in a family than we would expect by chance. Conditions which run in a family are usually caused by genetic changes. Our genetic code is the instruction manual for how to make a person, and is present in every cell in our body. Genetic changes make us who we are. For example, genetic changes will decide whether our eyes will be blue or green or brown. Genetic changes tell our body how tall to grow.

In some cases, a person can carry genetic changes which increase the chance of them getting cancer. For these people we can offer extra screening or other ways to make it less likely that they will get an untreatable cancer.

To help us decide whether you have an increased chance of developing cancer in your lifetime, we use information about you and your relatives (family history) as a guide. We look at:

- The number of people who have developed cancer in your family
- The ages the cancers developed
- The types of cancer in the family
- How closely related the relatives with cancer are

This information helps us decide whether any genetic testing is needed, or, more commonly, whether any extra screening is needed for you and your relatives.

**How will your data be used?**

A trained genetic counsellor, nurse, or doctor will review your family history information. They will use this information to decide if you or your relatives need any extra screening. This is known as a “risk assessment”. In most cases, you will then receive a letter telling you if you need any extra screening. If you do need extra screening the letter will tell you what this extra screening will be. In some cases, you may be offered an appointment in the genetics clinic. We might offer an appointment if we need more information, or if we want to offer you or a relative a genetic test.

**What information about my family will be stored?**

The information you give us will be stored in a secure, confidential genetics database. Information that could identify you will only be used to give you and/or your relatives advice on cancer risk. We will not share it with anyone outside of the NHS. We may use information that does not identify you for reporting or research to benefit patients of the future. Please ask us if you would like to know more. The data is stored so that if your information or your family information changes in the future, we can look at your information again to help us make a new risk assessment. The secure database is only accessed by trained health care workers supervised by the genetics department.
How long will your data be kept for?

Your data will be held securely on the genetics database which forms part of your health record. This is separate from your main health record and is only accessible to trained health care workers within the genetics department.

How can I ask for my data to be removed?

This data forms part of your health record and therefore is not subject to the right to erasure. You can apply to view your health record at any time by contacting the medical records department.

Why do you need information about my relatives?

We need information about your relatives and their cancer diagnoses to make the risk assessment. You should tell your relatives that you are providing this information about them, but you can provide it anonymously if you wish. We will never contact your relatives, without seeking your consent first.

If your relatives have died, knowing their names and date of birth can help us confirm their cancer diagnosis through cancer registries. If your relatives are alive, we may ask your relatives to sign a consent form to allow us to access their medical records. We will ask you to pass the consent forms on if this is the case. We will tell you the information we are gathering and why. Your information will only be used to give you and/or your relatives advice on cancer risk.