



## PARTICIPANT INFORMATION SHEET YOUNG PEOPLE AGED 12-17



### What is the UK Inflammatory Bowel Disease Nixon Twin and Multiplex Registry?

My name is **Dr William Blad**. I work with a team of doctors who are keen to learn more about Crohn's Disease and Ulcerative Colitis. We would like to understand why some people are more likely to get these diseases than others. We are collecting and storing information about people with these conditions and their family members. We are particularly interested in families where many people have these diseases, and twins where one or both twin has Inflammatory Bowel Disease. The IBD Nixon Twin and Multiplex Registry is a large computer file which stores this information. It also stores the names, addresses and emails of members of the registry.

At first we only collected information about adults. However the parents of several young people with these illnesses were keen to help. So we recently started collecting details about children and young people with inflammatory bowel disease too.

I have given more detailed information about the registry to your parent or guardian. You may read this too if you wish. We require consent from your parent or guardian for you to join the registry. However we will only include your details if you are also happy to take part. Please read this leaflet. If you would like to take part there is an agreement for you to sign at the back.

### So why do you want me to join the Registry?

You have been asked to join because you are from a special and unique family. We think you will be able to help us understand a bit more about why some people get Crohn's Disease or Ulcerative Colitis. Perhaps you have a twin, and one or both of you has Crohn's Disease or Ulcerative Colitis. Or perhaps you are from a family where three or more close relatives have inflammatory bowel disease. Such families are known as "Multiplex" families.

### **If I want to join the Registry what will happen?**

You and your parents or guardian will be given a survey to fill in about your health. We will also ask your family doctor or gastroenterologist to tell us some more about your health.

From time to time we will tell you and your parents or guardian about research studies you may want to participate in. However you do not have to take part in any of these projects if you do not want to.

### **Do I have to take part?**

No. If you do not want to take part no-one will be upset or angry. Whether you take part or not will not change the standard of healthcare you receive.

### **What happens if I agree to take part then change my mind?**

You can take your details out of the registry at any time. No-one will be upset or angry.

### **Will you share my information with other people?**

No. Only people working for the registry will be able to see your name and personal details. All staff have been specially trained to keep your information private.

When we learn useful information about inflammatory bowel disease from the registry this information may be presented at scientific meetings or published in journals. However things I have learned from you will be put with things I have learned from other members of the registry, and your name will not be included. There will be no way to identify you from such publications.

## Assent Form

- My name is **Dr Hannah Gordon / Dr William Blad**. I am trying to learn more about Crohn's Disease and Ulcerative Colitis. If you would like, you can be part of the IBD Nixon Twin and Multiplex Registry.
- I have invited you to be part of the registry because you are from a unique family. Perhaps you have a twin brother or sister, and one or both of you has Crohn's Disease or Ulcerative Colitis. Perhaps you are from a family where several close relatives have inflammatory bowel disease.
- If you decide to be part of the registry we will ask your parents or guardian to fill in a survey about your health. We will also ask your doctor for information about you. We will sometimes ask if you want to join other research projects. You do not have to join any of these projects if you do not want to.
- Other people will not be given your personal details, such as your name and telephone number
- Your parents or guardian have to give permission for you to be in the registry. However we will only include your details if you want to do it too. If you do not want to be part of the registry no-one will be upset or angry with you. If you join you can later decide you no longer want to be part of the registry.
- My email is [hannah.gordon@chelwest.nhs.uk](mailto:hannah.gordon@chelwest.nhs.uk) / [william.blad@nhs.net](mailto:william.blad@nhs.net). You can email if you have any questions about the registry, or decide later you no longer want to be part of the registry.
- I will give you a copy of this form to keep in case you want to ask questions later

### **Agreement:**

I have decided to be part of the registry even though I know I don't have to take part.

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**Print Name**

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**Signature of Study Participant**

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**Date**