

## **INFORMATION SHEET FOR YOUNG PEOPLE (12-15 years)**

We would like to ask you to take part in our research study called the **Airway Intervention Registry (AIR)**.

Please read this information carefully and talk to your mum, dad or carer about the study. If there is anything that is not clear, or you would like to know more, please ask us. Take time to decide if you would like to take part. It is up to you if you want to do this. If you don't then that's fine, you'll be looked after at the hospital just the same.

### **WHY ARE WE DOING THIS RESEARCH?**

We want to collect information on the health and treatment of people who have a specific airway problem called Respiratory Papillomatosis (where wart-like growths develop in the airway). We are doing this to make sure that the care of people with this problem improves.

### **WHY HAVE I BEEN ASKED TO TAKE PART?**

You have been asked to take part because you have Respiratory Papillomatosis, and we want to find a way of helping to treat you and others who have the same airway problems. We would like to get extra information about the treatments available for this problem. There are only a small number of people who are diagnosed with this problem each year, and an even smaller number are being treated regularly in hospital. We are setting up an online system to collect information from patients across the UK and we would like your permission to include your data.

### **DO I HAVE TO TAKE PART?**

No. It is entirely up to you. If you do decide to take part, you will be asked to sign a form to say that you agree to take part (an **assent form**) and your parents will be asked to sign a form to say that they agree for you to take part (a **consent form**).

You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive whilst in hospital. If you would like more time to decide, that's fine. You can tell us later if you want to take part.

### **WHAT WILL HAPPEN IF I TAKE PART?**

The medical staff at your hospital will enter your health information into the online system and keep it up-to-date. Some of the information we would like to know is about how your airway problem affects your daily life and how this new treatment changes your quality of life over time.

To get this information, your mum, dad or carer will be invited to complete relevant survey forms during your meeting with the medical staff. Completion of these survey forms is optional and your health information can be entered into the online system by medical staff without your parent or guardian taking part in the surveys. By taking part in this research study, we will make sure that all your information is treated as private and that it will not be shared with anyone else. Nobody will use this information to contact you.

#### WHAT WILL I BE ASKED TO DO?

You will not be asked to do anything extra as a result of the research study. By taking part all we do is collect information from you. Your nurse or doctor will give us information about your health and treatments, and your family members will be asked some questions about how you have been feeling lately.

#### WHAT HAPPENS WHEN THE RESEARCH STUDY STOPS?

We will collect all the information together and decide if it is useful in telling us if we can manage Respiratory Papillomatosis better in the future.

If the online Registry closes, your data will be returned to your local hospital team (if they want it), otherwise it will be deleted or destroyed.

#### CONTACT FOR FURTHER INFORMATION

If you have any questions about the use of your data, or if you change your mind and want your information removed, please contact your local hospital team (their details are provided below).

If you would like any further information, you should contact:

*[Place holder for Dr name at hospital/institution where research is being conducted:*

**NAME:**

**POSITION:**

**WARD:**

**TEL:]**

Thank you for reading this leaflet