

Are you affected by Recurrent Respiratory Papillomatosis (RRP)?

Did you know there is a national study collecting hospital data on all RRP treatments?

Background

Recurrent Respiratory Papillomatosis is a condition which causes wart-like growths in the airway which can make it difficult to breathe, speak and swallow. It is a rare condition (affecting 1-4 per 100,000 population) with no currently available cure. Little is known about how best to manage this condition. A national survey ([Donne et al., Clin Otolaryngol 2017](#)) showed that there are at least 16 different interventions for RRP in use in the NHS, however there is a lack of evidence on how safe they are and how well they work. To address this, the Newcastle upon Tyne Hospitals NHS Foundation Trust received funding from the NIHR Research for Patient Benefit (RfPB) programme to develop a secure online database to collect data from RRP interventions offered in NHS hospitals across the UK to see if we can determine which work best. Only NHS trusts/Health Boards can access this online database.

What are we collecting?

We are collecting data about treatments performed on RRP patients of all ages from around the UK, to help us understand more about which treatments work best for different patients. Patients must give informed consent

before their data can be entered (and are free to withdraw at any time). The treatment you receive will be the same regardless of whether you consent to your data being entered to the database or not. There is a patient website so that patients can submit voice quality questionnaires whenever they want, and also see how the study is progressing: <https://www.rrp.org.uk/>.

"I would like to encourage Otolaryngologists to participate in the UK RRP registry. In our experience a registry presents a significant opportunity to learn from the evidence gathered for the benefit of patients."

Craig Derkay 2018

How long is the study running for?

The database is currently funded until 31st August 2020. With your consent your hospital consultant can enter information about your treatment going back to January 2015.

What will you get out of this?

The data collected will be analysed so that we can understand more about how well the different treatments work for different patients. This will help to improve care for all RRP patients..

How do I join?

RRP is a rare condition, so we would like to collect data from as many patients as possible. If you would like your data to be included and your hospital consultant has not yet spoken to you about the study, please contact us and we can work with the hospital that is treating you to get them set up as a contributing Data Collection Centre. If you change your mind at any time that's not a problem – your data can be removed from the database. If you have any queries or concerns, please contact us:

"It affect what he does and what the whole family does"

"missing school...at hospital all the time"

"As parents we are always worried"

Quotes from parents of children with RRP

Email: NMPCE.Air@nuth.nhs.uk

Call: Emma & Kim on: 0191 213 8635.

