

The Airway Intervention Registry: Recurrent Respiratory Papillomatosis (AIR: RRP) data collection

BY ADAM DONNE AND STEVEN POWELL

Laryngeal papillomatosis remains a frustratingly difficult condition to treat. **Adam Donne** and **Steven Powell** tells us about a collaborative project aiming to enhance patient care.

The first UK Recurrent Respiratory Papillomatosis registry opened in April 2018 through the AIR (Airway Interventional Registry) platform. Patients are being actively recruited and there is much anticipation that this will provide benefit to patients and managing surgeons alike.

NICE produced Interventional Procedure Guidance on radiofrequency cold ablation for the treatment of RRP in 2012 [1]. They concluded that, "the current evidence on the safety and efficacy of radiofrequency cold ablation for respiratory papillomatosis is inadequate in quantity and quality." Therefore, if used, surgeons should inform their Trust's clinical governance leads and ensure patients understand the lack of evidence about safety and efficacy with clear written instructions. Furthermore, NICE recommended national data collection with the view of reviewing guidance on publication of further evidence.

There was a lack of understanding about all interventions for RRP in use in the UK. The best evidence had been the BAPO members' survey in 2006, with a response rate of 39% [2]. A repeat survey was required; with the support of ENTUK using SurveyMonkey®, a survey went out to all UK ENT surgeons. A response rate of 86% was achieved and 918 RRP patients identified. This work identified that cold ablation was used in only 3.3% of interventions in the period studied, with the microdebrider as the main intervention, but a total of 16 other

interventions were used in the treatment of RRP. Given the large response rate, a UK prevalence of 1.42/100,000 was estimated [3]. This was in line with the prevalence figures published by other countries [4].

NIHR Research for Patient Benefit grant (PB-PG-0416-20037) was awarded to develop an RRP registry in September 2017. Whilst not required for Research Databases, favourable ethical opinion was also sought. The AIR: RRP data collection formally opened on 1 April 2018.

Why do we need an RRP registry?

RRP is still an enigma despite the many publications on this condition. There is currently no cure and further research is needed. In order to do this, an understanding of disease burden to patients and the required healthcare resource to restore airway patency and manage symptoms needs clarification. Evaluating current therapies for relative effectiveness and safety allows a baseline to be established.

The human papillomavirus (HPV) vaccination programme will hopefully have a positive effect on reducing the overall prevalence of RRP, and there are novel RRP therapies on the horizon – a national registry would be ideally placed to evaluate the outcomes of these interventions.

How to get involved?

The UK AIR: RRP data collection is on the NIHR Clinical Research Network (CRN)

portfolio for children and we are currently seeking adoption in adults. This means that support is available to data collection centres to assist with screening and consenting patients. Portfolio adoption also means additional support to reach recruitment targets on time.

Individual ENT consultants wishing to contribute to the National AIR: RRP data collection should contact their local R&D department or contact the registry developer and host, Newcastle upon Tyne Hospitals, directly on NMPCE.AIR@nuth.nhs.uk Newcastle will then liaise with your organisation directly in order to set up your organisation as a data collection centre, and issue user accounts and user guides.

Written informed assent/consent is required from patients, or from someone with parental responsibility if the patient is under 16 years of age, before patient data can be entered. Retrospective data (dating back to 1 January 2015) can be entered as long as informed consent is gained. All original copies of signed assent and consent forms will be stored in the site study file at the recruiting hospital in accordance with local requirements. Two copies should be made; one given to the participant parent/guardian, and one entered into the patient's hospital notes. The AIR registry can only be accessed through an NHS computer. Each patient will need to be registered online and then visit data can be uploaded either from clinic or theatre.

The registry has been designed for ease of use, using structured pages with mostly tick boxes and interactive diagrams to ease data entry. A voice handicap index (VHI) questionnaire is featured in the registry to allow some appreciation of the effect of voice issues on quality of life for these patients. The registry contains an anatomical diagram which can be clicked on to allow the auto-calculation of Derkay

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score to give a standardised, objective measure of extent of disease at each theatre visit. Graphs of anatomical Derkay score and VHI allow a summary of the patients' condition over time.

What benefits does an RRP registry offer?

From the surgeon's perspective, the registry will allow a better understanding of the patient's condition by delivering results for scores on how voice is affected and a more objective approach to assessing disease severity with Derkay scoring. The graphical representation of the clinical course allows an instant appraisal of the patient's condition over time.

Identifying the safest and most effective treatments for RRP will influence care of RRP patients in the future, reduce complications, hospital stay, hospital visits, unexpected A&E/GP visits, and maximising the time between interventions and improving the patient's quality of life. There is also a patient facing website under development (www.rrp.org.uk) which will allow patients to go online and complete voice assessment questionnaires from home, using a secure and randomised ID. Patients will also be able to track progress of the study (recruitment and results so far) via this patient facing website. Patients with RRP and their families are often keen to be involved in innovations around RRP and a patient portal will help to address that need and empower them.

The registry will allow a UK evaluation of RRP interventions, providing a vital resource for demonstrating benefits of future therapies. The registry is now recruiting patients and all surgeons are invited to take part.



Figure 1. Sites around UK that are currently involved with the AIR-RRP registry.
Green – actively recruiting sites
Amber – sites ready to recruit
Red – sites that are in the process of setting up

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AUTHORS

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Adam J Donne PhD, FRCS (ORL-HNS),

Consultant Paediatric Otolaryngologist, Alder Hey Children's NHS Foundation Trust, Liverpool, UK.

E: Adam.Donne@alderhey.nhs.uk



Steven Powell, MSc FRCS (ORL-HNS),

Consultant Paediatric Otolaryngologist, The Newcastle Upon Tyne Hospitals NHS Foundation Trust, UK.