

Meeting unmet needs for Adenoid Cystic Carcinoma ('ACC') Research in the UK and beyond

Emma Kinloch^{1*}, Dr Robert Metcalf²

SUMMARY

Adenoid Cystic Carcinoma ('ACC'), a **rare** Salivary Gland Cancer ('SGC'), affects around 5 in every million people in the UK. Median 5-year overall survival rates are 13 years from diagnosis. If patients develop metastasis, **median survival is between 3 to 5 years**. It generally grows slowly, along nerves, but is **relentless**. Patients can often find they have metastatic disease many years (often over 10 years) after treatment of their primary tumour. Surgery with or without radiotherapy is the main treatment for localised disease. Currently chemotherapy regimens have very limited efficacy for recurrent or metastatic disease. There are **no clearly associated risk factors** and no links with gender, age, ethnicity, or lifestyle. **Little is known** about its biology, there are **no targeted drug therapies available**, and there is **limited research** into the condition. Until recently there was **no specific patient support** available in the UK. To address this unmet need Salivary Gland Cancer UK was founded.

METHOD

In April 2019 Salivary Gland Cancer UK ('SGC UK') was launched. This unique collaboration between a medical oncologist and a patient advocate uses co-production to build an active patient and research community. SGC UK is working to understand the biology of SGC's, advance research, develop new treatments, and support the patients and carers that are affected by them. Developing networks, providing reliable information and pushing forward.

National Links include the National Cancer Research Institute ('NCRI')

A **biobank** of tissue samples is being built to feed international research

Patient and clinician **consultative committees** being established to drive forward initiatives

Regular in person and virtual meetings: around 50 patients and carers, researchers and clinicians gather 4 times a year

Patients from all over the UK and beyond are being referred to the **specialist hub** at The Christie NHS Foundation Trust

We facilitate **clinician and researcher engagement** via our meetings

Clinical Trials for ACC patients opened at The Christie hospital

Active research in **Immunology & ACC** at the University of Manchester

Researcher – Patient discussion days: output informs our key research priorities

Fig 1: **RESULTS**

International Links include International Rare Cancers Initiative ('IRCI'), European Reference Network for Rare Adult Solid Cancers ('EURACAN') & EURORDIS

CONCLUSION

Launching Salivary Gland Cancer UK as a unique collaboration is addressing the unmet needs for ACC research in the UK and beyond, for clinicians, researchers and those affected by this rare cancer. A valuable database is being established to drive forward national and international research. Reliable information and support is being provided for patients, their carers and treating clinicians. Visit www.salivaryglandcancer.uk to join our network, get involved or keep updated. You can also join us on Twitter @SGCancerUK, FB @SalivaryGlandCancerUK or email: hello@salivaryglandcancer.uk

AFFILIATIONS

1 NCRI Consumer Lead, EURACAN ePAG

2 The Christie NHS Foundation Trust (Medical Oncology), The University of Manchester