

Meeting unmet needs for Salivary Gland Cancer ('SGC') Research in the UK and beyond

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SUMMARY

There are >23 types of rare Salivary Gland Cancers ('SGC's'), yet they account for less than 0.5% of new cancer cases globally each year. Adenoid Cystic Carcinoma ('ACC') is the most common and 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 these unmet needs 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.

We facilitate **clinician and researcher COLLABORATION** i.e. 'the action of working with someone to produce something'

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

Clinical Trials In December 2019 the AL101 trial opened at the Christie. Other trials are in development

Regular in person and virtual meetings: around 30-50 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

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

Initial focus on ACC **expanded to support acinic cell carcinoma, ductal & secretory carcinomas**. Further expansion planned in 2021

Dedicated researcher investigating the **Immunology & ACC** at the University of Manchester

Researcher – Patient discussion days: output informed key research priorities & aims launching in 2021

Fig 1: **RESULTS**
April 2019 - present day

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

CONCLUSION

Launching Salivary Gland Cancer UK as a unique collaboration is addressing the unmet needs in the UK and beyond, for clinicians, researchers and those affected by these rare cancers. 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

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