

# Library and Knowledge Services case study

# Royal United Hospitals Bath NHS Foundation Trust*:*

# Surveillance of renal TSC related AML

Date *[06/07/2021]*

Date of interview: 11/05/2021

## Reason for enquiry

RUH, Bath runs a Supraregional Tuberous Sclerosis Service for Adults and Children.

Patients with TSC related angiomyolipomas are scanned annually throughout their entire lifespan (as suggested by the international guidelines).

Logistically it can be very difficult for people with learning difficulties (50% of the cohort) to obtain a general anaesthetic scan. On some occasions the patients with LD can be discriminated against in terms of not being offered a scan, but equally having a scan can be very distressing for this cohort. The TS specialists intervene, when needed, to ensure the scan is carried out, but sometimes also have to make a judgement call with regard to balancing risk/benefit for the patient.

Dr Loh felt that that once TSC patients are above 50yrs old they don’t get a bleed or complications from their renal AML.

The Academy Library was asked to investigate this, to search for any evidence of anyone above 50yrs old experiencing bleeding from their renal AML.

## What the knowledge and library specialist did

An extensive search was carried out on Medline and EMBASE looking at all case studies and articles concerning TSC patients with renal AMLs.

No case studies could be found that explicitly mentioned TSC AML bleeds over 50yrs.  There were some articles where it was impossible to tell age, or if TSC related. Evidence was provided of general risk factors surrounding bleeds. Detail of five studies was provided where there was mention of age and bleed in this older age group. All were under 60yrs old. One study was unclear if TSC related. One had mention of haematuria, rather than haemorrhage.

***That is really useful for me clinically…thanks again for your amazing efforts***

# Impact of input from the library and knowledge service

The information provided from the literature search found that after 60yrs old, the chances of complications is reduced dramatically and will help inform how the TS service proceeds with practice.

## Immediate Impact

* Information supplied to guide practice.
* Dr Loh’s thoughts that bleeding risk and complication lessens over 50yrs old were confirmed. There was minimal evidence of bleeding in 50-60yrs age-band. No evidence over 60 yrs of age.

## Probable future Impact

* Less unnecessary general anaesthetic scanning.
* Therefore, less need for hospital stays.
* Consequently, less distress for TS patients with LD.
* Resulting opportunistic cost savings for those that need the scanning slots.

## Name and Job Title:

Name: **Dr Ron Loh**

Job Title: Consultant Paediatrician / Joint Head of the Supraregional TSC Service

## For further information on how you can get similar support contact your local NHS library and knowledge service.

**Submission Details**

**[To be completed by Knowledge and Library Service at the point of submission]**

Name of Organisation Royal United Hospitals Bath NHS Foundation Trust

Knowledge and Library Service Contact Email *[lisa.hirst2@nhs.net]*

NHS Region South West

Title of Case Study *Surveillance of renal TSC related AML*

Sector Acute

Group Impacted Medical and Dental

Impact Types [Please select any which apply]

Contributed to personal or professional development.

Contributed to service development or delivery.

Facilitated collaborative working.

Health Information for Patients, Carers and the Public.

Improved the quality of patient care.

Mobilising evidence and organisational knowledge.

More informed decision making.

Productivity and efficiency.

Reduced risk or improved safety.

Saved money or contributed to financial effectiveness.

Improved health and wellbeing of staff and learners

I have consent from individuals referred to in this case study to share details nationally for advocacy and promotion.

Yes