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# Keeping up-to-date with the latest research

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Session Three is repeated at the following times:

11:30 to 12:20 (50 mins)

13:20 to 14:10 (50 mins)

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## Overview

This session will look at how to access reliable research on your area, and how to make sense of the research you find. It will also look at ways to search for suitable clinical trials and access results from concluded studies.

## Who will find this session relevant?

Any Rare Disease patient, carer or individual interested in finding and understanding the research that's out there. Whether you want to find out about research into a particular drug, learn more about a condition or champion new research, this session will help you understand the resources available.

## Covering the following

Searching for Rare Disease research, accessing information, understanding how research papers are structured.

### Search

- Why it is difficult to research rare diseases
- By **condition**- what if drug 'Y' could treat condition 'X'
- On **drugs** and **symptoms**- for example, elevate shake and tremors
- Making use of trial registries

### Access

- What's accessible, what's not and suggestions on how to get around paywalls
- Researching treatments available outside the UK
- Top Tips on finding/reaching out to researchers and authors
- Setting up alerts for information/research relevant to you

### Read

- Making sense of scientific papers
- Judging research quality

### Translate

- Advice on interpreting research- particularly for a lay audience
- Other examples of information/ research you can share

## Activities

### To include:

- Demonstrations, discussion and Q&A

## Isla Khun



Head of Medical Library Services  
University of Cambridge Medical Library

## Dr Pooja Takhar



Head of Research  
Tuberous Sclerosis Association (TSA)

*Full biographies can be found  
in the conference brochure*