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# Communicating rare disease stories and research

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Session One 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 cover use of storytelling, for communicating research. **Story telling** is a way of expressing real life experiences about the issues facing those living with a rare disease. **Communicating research** will look at ways to disseminate relevant information/research outcomes and how you can influence stakeholders.

## Who will find this session relevant?

Those living with a rare condition, a family member/carer of someone who does, or those trying to help a rare disease patient. Anyone who wants to reach out to an audience and maximise the effect of each story by using a variety of media. Individuals who have to translate the science for members of the public or decision-makers.

## Covering the following

### Story telling

- What the story is, why it matters and why now
- Grabbing audience attention- painting a picture
- Sparking debate through personal experience
- Using the most appropriate communication channels (print, social media, film etc.)
- Analysing the effects of your story

### Communicating Research

- Who needs to know and how much they need to know (researchers, patients and carers, public, government, funders, industry)
- How you are going to reach your different audiences
- How best to trigger a response
- Top tips- keep language simple, focus on key messages
- Pointers on conveying the science.
- Understanding how your communication can influence policy (yes, it's that important!)

## Activities

### To include:

- Exercise & Discussion
- Q&A

## Lucy Lloyd



Communications and Knowledge Exchange,  
Department of Public Health and Primary Care

## Jayne Bressington



Vice Chair GIST Cancer UK and Patient Director, PAWS-GIST

*Full biographies can be found in the conference brochure*