

Recruiting and engaging research participants

RECRUITING PARTICIPANTS

We know that recruiting participants for research can sometimes be challenging. That's why Tourettes Action have set up a [Research Participant Registry](#) for people willing to be research participants or lay reviewers for Tourettes Action research grants. This forms part of Tourettes Action's Patient and Public Involvement Programme.

Tourettes Action can help your recruitment by sharing your research with our supporters.

How we do this

- by emailing our network of research supporters across the UK (or specific areas)
- by featuring your project on our website and sharing it with our online community

What you need to do

We ask that researchers make initial contact with Tourettes Action's research manager, Dr Seonaid Anderson to discuss your project seonaid@tourettes-action.org.uk

You will be asked to provide:

- full ethical approval or support letter
- patient information sheet and consent form

ENGAGING PARTICIPANTS

Social media

“Ten years back, most of what you saw and shared online was text. Then we went through a phase where most of it was photos. We believe that in five years...most of what people consume online will be video.”

Mark Zuckerberg, Facebook CEO (July 2016)

As a researcher supported by Tourettes Action, we want to help you engage as many people as possible for your study. Our social media platforms – primarily Facebook and YouTube – are by far the most effective way we engage existing and new supporters. We know that our audience responds well to personal stories and video narratives that provide instant, visual engagement of a particular topic.

Research is one topic that is in need of more visual stimulation to get people interested in the subject, and converted into research participants.

Tourettes Action has a playlist on their YouTube channel dedicated to Research. This is where your videos will feature, in an organised section that will be specific to your study.

<https://www.youtube.com/user/UKTourettesAction/playlists>

You don't need to have flashy equipment or film-making aspirations to create a valuable piece of high quality video that can capture people's attention.

Below are some guidelines about creating video content to support and promote your research, and help recruit participants.

What, How, Where?

What might you make videos about?

- It could be a visual insight into the 'lab' or clinic so people get to see where research is done, supported by commentary.
- Short interview with one or two researchers/clinicians involved in the research, giving a brief summary about the study, what's inspired it and what you hope it will achieve for people living with TS.
- An open appeal by you the researcher, summarising in Plain English how research has contributed towards developments in our understanding and approach to treating TS.
- Short interview with participants in your study, asking questions that provide insight into the positive aspects of being involved in research.
- Videos need to be short and punchy, we recommend 1 minute - up to 2 minutes max.

How do I make videos?

- Most smart phones have a good in-built camera. This is all you need to create your video
- The camera must be held steady to ensure a good visual quality. You can prop the phone against something or use a grip which can be purchased online at a very affordable price.
- Once you have made your video, you need to send it to Tourettes Action's content manager. The video will be edited to include titles (your name and professional title, title of research study and call to action for people to get involved)
- You can send video files using a free online platform called wetransfer.com that allows you to send large files, or send via www.dropbox.com – another free file sharing platform. Send to helen@tourettes-action.org.uk

Where do I film?

- You must make sure that you record in a quiet space so as to filter out any background noise that will affect the sound quality. Avoid walking around with the camera as this gives you little control over visual and sound quality.
- When talking to the camera it is best to have a focused head and shoulder shot of yourself.
- Make sure the space you are filming in has as much natural light as possible.
- Do a quick test of the sound quality by recording a short clip of you talking, play it back and make sure the sound is clear and of good volume.
- Be aware of your proximity to the speaker as this will affect the volume
- If you can film shots of the 'lab' 'university building' 'equipment/technology' – any visual aids that bring the research study to life

- As always please ensure you have asked permission from anyone you are filming beforehand.

This is an exciting new frontier for Tourettes Action and its research partners. We are confident that it will help engage a wider audience with TS research, and look forward to working with you to help your study flourish.

Writing

Research participant blogs and photos can give an insight into their experiences. If you have anyone saying really positive things about your research ask them if you can write it down and use their words, even anonymously. These quotes can be incorporated into our website on the research pages, and we can use them to promote your research on social media.

Here are some examples from TA webpages:

'When my Dad told me about the research I was chuffed and I thought it was brilliant as I had tried everything so far'.

'I feel much better now and once I had been involved in the research my attitude changed. I was out and about and went to the gym and didn't let it (sic TS) stop me from living my life'.

There are a variety of [blogs](#) and [photos](#) on the TA website which encourage other people to get involved in research too

You can use quotes from parents if you have their permission:

'By involving your child in research you give them a feeling of self-importance and that they are contributing something by giving something to other children with TS'. By children with TS and their parents accepting their TS and by trying research they are showing there IS going to be an answer'.

If you have any further questions with regards to **engaging people in your research** and/or using video promotion/marketing please contact: helen@tourettes-action.org.uk

Or

Research Manager Seonaid@tourettes-action.org.uk