

CLAPA Experts Panel

Background

User involvement and working closely with the NHS are core values of CLAPA's. It's extremely important to us that the materials we produce (as well as other publications) are reliable, sensitive and comprehensive. This is why we work hard to make sure we consult with parents, patients and health professionals before making any new materials available to the public.

This doesn't just include medical information, it can also be things like surveys or presentations. We want to be the voice of people affected by cleft lip and palate in the UK and to provide them with the support and information they need – but we need your help.

About this role

As part of our Experts Panel, you will be asked to read and comment on drafts of information products (e.g. new leaflets) as well as other materials as necessary. We'll tell you what kind of feedback we're looking for, but we'll also take on board any other general comments you make. What matters most is that you'll be able to use your knowledge and experience to improve things for others using our services in the future.

You will not be required to comment on any particular materials, and can ask to be removed from the panel at any time.

For medical professionals: We'll ask you to use your knowledge to make sure our materials are medically accurate. We may also ask you specific questions if they are raised by a member of our community and we can't find a reliable answer elsewhere. We will work to recruit multiple specialists within a particular field across different teams to make sure a) we are covered when certain Experts are not available and b) our work is seen by as many specialists as possible before publication.

For patients and parents: You are an expert on your own experiences with cleft lip and palate. No matter how much in-depth medical knowledge you may or may not have, you know best how you felt at certain points in your journey and what would have helped the most. This is why we need you to use your own experiences to review relevant materials such as information leaflets and give us whatever feedback you can. We need people of all backgrounds, ages, reading levels, medical knowledge, and connection to cleft.

Please note: This is not an official CLAPA Volunteer role. CLAPA Volunteers are recruited, inducted and supervised using a set process by our volunteering team. As part of the CLAPA Experts Panel you will not be expected to follow this process as you will not be representing CLAPA at events, etc. Rather, in this role, you will be representing yourself and your experiences only, and will be reporting to CLAPA's Information Team rather than the Volunteering Team.

Key Tasks

- RELEVANT INFORMATION PRODUCTS
 - o Critically reviewing drafts of CLAPA's health information before publication using a checklist and adding comments where appropriate.

- Critically reviewing the contents of existing information products as part of CLAPA's 3-yearly review cycle where necessary.
- Commenting on design and layout of new information leaflets
- Reporting any general comments or concerns to CLAPA's Information Manager
- OTHER MATERIALS
 - Responding to specific queries where possible
 - Critically reviewing drafts of other materials using your experience and knowledge to ensure they are appropriate for our community and/or the general public.

We're looking for people who are:

- Cleft-specialist medical professionals AND/OR personally connected to cleft lip and palate (e.g. parent, patient)
- IT-literate – able to use e-mail and internet, and able to digitally comment on documents, e.g. using Word or Google Docs.
- Able to maintain confidentiality where necessary.
- Able to work independently and to a specified deadline.
- Able to consider the perspectives of many different people when reviewing a publication, especially people with lower levels of literacy.
- Experienced with writing and editing documents, particularly those aimed at the general public (desirable but not essential).

Time Requirements:

- You can pick which products you would like to work on (and/or questions to respond to) when we send out the requests. There are no set time requirements.
- We will provide a deadline by which we would expect to receive any feedback, so you can make informed decisions about whether or not to participate in each case.

We can offer you:

- A unique and rewarding experience where you get to use your experience to help shape the health information available to our community
- Great experience for your CV or university application

Recruitment and Retention:

- Anyone who fits the criteria can join the Experts Panel. They must email the Information Manager (currently Anna Martindale, anna.martindale@clapa.com) explaining who they are, what their connection to cleft lip and palate is, and if they have any other relevant areas of expertise, e.g. if they've had a particular kind of surgery. The Information Manager will add them to the list and will be in touch when any relevant materials are in need of review.
- CLAPA Experts can ask to be removed from this list at any time.
- If an Expert doesn't provide any response to three requests , we will be in touch to ask if they would still like to be contacted for these purposes. If we receive no response after a week, they will be presumed to have no further interest and will be removed from the list. You can ask to be re-added at any time.