

CLAPA Consultancy and Bursary Service 2024-25



Introduction

CLAPA's Consultancy and Bursary Service is aimed at supporting NHS and Research Teams with their Patient and Public Involvement.

'Patient and Public Involvement' (PPI) is a vital part of conducting research into conditions like cleft lip and palate. It is important and valuable that people directly affected by services, information and research are involved in its development. The cleft community shares this sentiment; according to CLAPA's 2023 Survey, where 95% agreed it was 'important for cleft researchers to get feedback about their projects from people affected by cleft'.

With this in mind, CLAPA supports patients, families and members of the public to be actively involved in research projects and service development, by sharing their experiences and providing valuable first-hand insights to help shape development focus and design.

CLAPA's Consultancy Service aims to foster a collaborative spirit by creating beneficial partnerships with others working to improve the lives of people born with a cleft in the UK. This document lists packages of support, but we can also design a bespoke package to suit your needs.

If projects do not have the funding for this work, CLAPA offers a **PPI Bursary** to the value of £490 to allow eligible applicants to get support from CLAPA.

The decision about whether or not to promote a particular study or accept a piece of work is at CLAPA's discretion. If you are not sure whether your project would be appropriate, please get in touch for an informal discussion.

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About CLAPA

The Cleft Lip and Palate Association (CLAPA) is the **national charity supporting people born with a cleft and their families in the UK.**

CLAPA is there from the moment of diagnosis and throughout the entire cleft journey. We provide reassurance, information, a welcoming community and opportunities to connect with other families, children and adults born with a cleft.

CLAPA has over 40 years of experience in **helping the cleft community use their voices to impact on the future of cleft care.** We have direct access to a large community of patients, parents, carers, and other family members affected by cleft, including:

- Active social media profiles with over 30,000 combined followers and a reach of two million people per year.
- 3,000 'CLAPA Connect' e-newsletter subscribers
- 180 'CLAPA Voices' members with a specific interest in research involvement
- Online support groups for Parents & Carers and Adults born with a cleft with over 14,000 members
- Regular PPI groups focusing on CLAPA services, including the Children and Young People's Council (CYPC), Adults' Focus Group (AFG), Family Focus Group (FFG) and Young Adults Focus Group (YAFG).
- Co-ordination and/or membership of a number of external PPI groups including in partnership with the NHS. These groups include the Cleft Development Group Patient Engagement Group (CDG PEG), Cleft Care Scotland Patient Engagement Group (CCS PEG), CLAPA & Cleft Collective Patient Consultation Group, Clinical Studies Group
- Regular online events aimed at all sectors of the cleft community which average 700 attendees each year.
- In the year 2023/2024 our research ads over email had a 63% open rate. A 'good' open rate for email marketing is considered to be 17-28%.

CLAPA is uniquely placed to support people wishing to work with the cleft community due to our wider reach, independent status, and the skills and experience we have in house.

CLAPA's Communications Team are skilled in translating complex topics and making them relevant and appealing to the UK cleft community. We make use of our digital marketing skills alongside our knowledge of the cleft world to ensure the right opportunities will reach the right people.

As the UK's cleft support charity, we reach out to our 20,000 strong community and regularly collect data on their needs and concerns through surveys, feedback collection and discussions in private support groups.

"It's a privilege to be involved in something like this, and it was quite simply inspiring to see how engaged everyone was. Both you and [the researcher] made clear that you really heard, not only the points made, but the bigger picture for each contributor."

CLAPA patient rep taking part in a research consultation group

The Engagement and Services Team are plugged in to the needs of the UK cleft community. Our direct contact with people affected by cleft at all stages of their journey means we can advise on which aspects of which projects will be most appealing to those we support as well as what the barriers to participation might be and how to overcome these.

[Learn more about CLAPA.](#)

Packages for Researchers

Our dedicated Consultancy Service can support your PPI needs in a variety of ways. Below you will find details of our support packages which have been developed and informed by our previous consultancy work.

We also deliver a **bespoke service** to meet the unique challenges of your research and PPI needs.

"CLAPA have been invaluable in helping our research to reach the wider cleft community. Their enthusiastic support in sharing information about our research has contributed significantly to our research's recruitment and I would hope that their consultancy will be able to help shape the research activity of my team and wider colleagues in the future"

Researcher who used CLAPA's Consultation Service

Advertising Research Study (Basic)

Promoting your study or initiative on our website

- Basic information about study added to [CLAPA Voices Hub](#)

Cost: FREE

Recruiting Participants

Advertising for patients to join a research study

- Review study
 - Liaison with researcher regarding study and participants required
 - Review and advise on any materials e.g. surveys/information leaflets etc. (maximum 2-3 leaflets and 1 survey of up to 10 questions, or up to 1 hr of staff time)
 - Advising on changes needed to promote accessibility and inclusion
- Promote study
 - Creation of advert (information provided by researcher using CLAPA's standard form)
 - Promotion of study in our social media groups/pages/newsletter/CLAPA Voices
 - Advert added to CLAPA Voices Hub

Cost: £245

Study Advisory Group

Setting up a Study Advisory Group to provide feedback on a research idea (1 meeting)

- Set up and recruit for group
 - Liaison for information to run the focus group and to inform the advert
 - Advising on changes needed to promote accessibility and inclusion
 - Creation of advert and expression of interest form
 - Promotion of focus group in our groups/newsletter
 - Administrating recruitment of members (max 20 people) for the focus group
- Prepare for meeting
 - Optional training where required to support focus group members to participate
 - Circulating meeting information/pre-reading materials for comment/dates and zoom details
- Hold meeting
 - Facilitating the meeting/dealing with tech
 - Keeping record of attendees for future meetings
 - CLAPA staff member also ensuring the wider cleft community view is included
 - CLAPA staff member also reading accompanying project documentation

Cost: £490 (full day)

Further meetings: approximately £245 if no new recruitment is required; £490 if new recruitment required; get in touch for a bespoke quote

"CLAPA have been incredibly helpful and supportive in promoting our research. Through their assistance, our research team have been able to recruit members of the cleft community for our study with ease. I would highly recommend CLAPA's consulting services to fellow researchers."

Researcher who used CLAPA's Consultation Service

Bespoke Work

CLAPA can put together a bespoke package to suit your needs. This work will be completed at the following rates:

- ½ day (minimum) £245
- Full day £490

Make an Enquiry

[Make an enquiry about CLAPA's Consultation Services](#)

Packages for NHS Services

Why should you involve Patients in NHS decision making?

[Patient and Public Involvement: a toolkit for GPs \(BMA\)](#)

About Patient Engagement Groups (PEGs)

Patient Engagement Groups (PEGs) are a way for NHS services to ensure the patient voice is included whenever decisions are made about cleft care.

In May 2022, CLAPA set up a PEG with the [Cleft Development Group](#) (CDG) to identify and raise issues within cleft services at a national level within the UK.

In order to support this work and ensure cleft services at local levels are meeting the needs of patients, NHS Cleft Teams should consider developing their own Patient Engagement Groups (PEGs) to ensure that the patient voice is heard. CLAPA can support this work and help with the set up and, if required, the ongoing coordination and facilitation of these groups.

"It's quite a privilege to be involved in something like this, and it was quite simply inspiring to see how engaged everyone was. Both you and [the researcher] made it clear that you really heard, not only the points made, but the bigger picture for each contributor.

That's so validating, I can only speak from my own experience, but to be in the company of people who "get it" really is a new level of feeling understood. For that to come out of our first proper meeting, as such, was quite a revelation. Thank you to all involved, especially those of you facilitating the meetings and feeding back to CDG colleagues."

Patient Representative who was born with a cleft

CLAPA can also support one off pieces of work where it is valuable to have the patient voice included.

Single Patient Engagement Group Meeting

We will organise, recruit for and facilitate a single online meeting.

- Recruit patient representatives
 - Liaise with NHS service to fully understand needs, advise on accessibility and inclusion concerns, and agree other details
 - Create advert and expression of interest form, and promote group through all appropriate channels
 - Administrate the recruitment of people with lived experience to the group
- Preparing for meeting
 - Identifying any additional requirements and offering optional training to enable everyone to participate
 - Circulating meeting details and pre-reading materials

- CLAPA Staff member to read materials and make other preparations for meeting
- Handle all administration involved with inviting members
- Hold meeting
 - Host and Chair the meetings
 - Keeping record of attendees for future meeting

Cost: £490 (1 day)

Follow up meetings to the above: £245 per meeting when no additional recruitment of members is required and £490 when additional recruitment is required.

Full Patient Engagement Group Set Up & Management

We will set up and manage a new PEG group for your NHS service for one year (max 3 meetings).

- Recruit Patient Representatives
 - Liaise with NHS service to fully understand needs, advise on accessibility and inclusion concerns, and agree other details
 - Create advert and expression of interest form, and promote group through all appropriate channels
 - Administrate the recruitment of people with lived experience to the group
 - Create Terms of Reference (for and with the group) and ensure all members sign
- Prepare for meetings
 - Liaise with NHS service and group members to agree meeting dates (to include up to three meetings in the first year, including one induction meeting)
 - Identifying any additional requirements and offering optional training to enable everyone to participate
 - Circulating meeting details and pre-reading materials
 - CLAPA Staff member to read materials and make other preparations for meeting
 - Handle all administration involved with inviting members
 - Maintain any documents developed by group e.g. terms of reference, lists of actions, etc., or support a group member to take on this role
- Hold Meetings
 - Host and Chair the PEG meetings via Zoom (a 1hr group x 3 meetings)
 - Keep records of attendance/hours
 - Taking notes and actions
- Extra Support
 - Recruit new members throughout the year as needed and provide 1:1 inductions
 - Liaise with patient representatives as and when required, including providing additional support and training
 - Develop a bespoke training session training for NHS staff (1-2 hours, can be provided for new staff at a later date for additional cost)

Cost: £2,450 (5 days) or £1,820 with CLAPA's bursary subsidiary

To encourage new NHS Service PEGs, CLAPA is providing a bursary of £490 to subsidise the cost of setting up a new group.

Ongoing support for year 2 onwards agreed based on availability /costed if required.

Additional training for new staff Cost: £490 per group max 10 people/£140 per person

Attend Single Meeting

A CLAPA representative will act as the voice of the cleft community in a single steering group meeting, Clinical Excellence Network meeting, or any other relevant meeting.

- CLAPA Staff to use expertise to represent the patient voice on specific or general matters
- CLAPA staff time to prep and read papers and speak to our community to gather relevant information in advance of the meeting.

Cost: From £245

Patient Representative for Interview Panel

We can recruit a patient with relevant lived experience to sit on an interview panel when recruiting new staff

- Create/amend graphics for social media posts in line with CLAPA policy
- Create text to be shared
- Add opportunity to CLAPA Voices hub webpage
- Send opportunity to CLAPA Voices via newsletter/text (180+ individuals with a strong interest in such opportunities)
- Promote opportunity to the community on social media (20,000+ individuals)
- Promote the opportunity to general mailing list (where we need to increase the direct reach)
- Monitor and respond to comments on the social media posts

Cost: £245*

* Researchers/Services are responsible for paying the PPI representatives for their time (if appropriate) and any out of pocket expenses such as travel.

Bespoke Work

CLAPA can put together a bespoke package to suit your needs. This work will be completed at the following rates:

- ½ day (minimum) £245
- Full day £490

Make an Enquiry

[Make an enquiry about CLAPA's Consultation Services](#)



PPI Bursary

To facilitate relevant and meaningful Patient and Public Involvement (PPI) in cleft research and cleft services, the CLAPA PPI Bursary has been set up to support researchers and clinicians working within cleft research and NHS Cleft Teams who wish to increase and improve their PPI.

Through its dedicated Consultancy Service, CLAPA assists with the coordination, facilitation and advertising of PPI. The PPI Bursary was developed to support those that have been unable to access funds elsewhere to support their PPI work.

Applicants who are unable to access funds elsewhere can apply for a bursary of up to £490 worth of support from CLAPA's Consultancy Service. If applicants are successful, the agreed bursary will entitle the recipient to receive PPI services from CLAPA up to the maximum value of £490 only. The bursary is not redeemable for cash.

Who can apply?

- An **undergraduate student** who has the support of a university and/or clinical team and a named supervisor. You will be asked to provide a supporting statement & signature.
- A **postgraduate student** who has the support of a university and/or clinical team and a named supervisor. You will be asked to provide a supporting statement & signature.
- A researcher/clinician initiating a **one-off project/a pilot study/initial PPI** work that will lead to an external grant.
- Researchers looking to **develop their research question and materials** before applying for funding and seeking patients views on the research.
- **Cleft Teams/NHS clinicians** wishing to involve patients/patient representatives in service development.

PLEASE NOTE: If your application is for PPI related to research, applications need to be made at the earliest stage of your research/project; we cannot support PPI costs if you have omitted them from existing funding grants.

What can a Bursary be used for?

The bursary, up to a maximum of £490, can be redeemed against the balance of any of CLAPA PPI services. Where the cost of the service exceeds the bursary, CLAPA requires the payment of the remaining balance in full.

Activity	Consultancy Service Fee
a social media post across CLAPA's channels to advertise your project using appropriate language/terminology (more information)	£245

A single advisory focus group for a study/service (more information)	£490
Setting up a regular Patient Engagement Group for one year (more information)	part payment only up to a maximum of £490 (remaining £1,960 required)

You may also wish to propose a bespoke package of up to a day's worth of support from CLAPA's Consultancy Services.

How to apply

[Complete the application form linked on our website.](#)

The funds available for CLAPA bursaries are limited, therefore there is an expectation that you will have tried/explored other options for funding this activity before you apply. We will consider both part and full funding if all alternative options have been exhausted and you haven't reached the final total required.

Possible sources of funding for PPI activities could include:

- NIHR (e.g. NIHR has a specific call for PPI work prior to NIHR applications)
- Local Hospital Charity
- University
- Research capability funding (through NHS trust)
- Professional bodies small grants to support CPD which may include supporting PPI
- Cleft team/hospital funding
- Other research related organisations e.g. the [Council for Allied Health Professions Research \(CAHPR\)](#), [NIHR Applied Research Collaborations \(ARCs\)](#)

Additional points to consider

If you are doing your PPI as part of developing a research proposal/funding application, it would be reassuring for CLAPA/patients/carers if your proposed study or project is likely to develop into a robust research proposal.

To help with this please consider:

- Discussing your project idea within the Early Career Researchers Group (ECRG)
- Submitting your project proposal to the Cleft and Craniofacial Clinical Studies Group (CSG) for review when complete
- Or submitting your project to another appropriate place for review – i.e. University / Centre for Appearance Research (CAR), etc.

Assessment Panel

CLAPA Staff Member – Gillian McCarthy, External Engagement Coordinator

Patient Representatives including a maximum of 2 parents, 2 adults, 2 young people/young adults

Research clinicians – Sophie Butterworth, CRANE Clinical Fellow

The research clinicians will only be sent the applications which include research and will not be sent applications from Cleft Teams or relating to Cleft Services.

Assessment Process

CLAPA collates forms on the first working day of the month and sends applications to the panel.

The panel considers the following from the application:

- Do we feel the topic is valuable to the cleft community?
- Is it clear what the applicant wants PPI for?
- Is it feasible for CLAPA to provide what they are asking for?
- Is the PPI request valuable as it stands or would we recommend a different approach to PPI?
- Have the applicants clearly explained how they will use PPI in the future and CLAPA's involvement?
- Would you support this application for a PPI Bursary? Why?
- How much should be awarded?

The panel submits their thoughts and sends to CLAPA by the last working day of the month.

The panel aid CLAPA in making a decision, however CLAPA will make the final decision.

CLAPA contacts the applicants by the 15th of the following month with outcome and any feedback.

What happens next?

Successful applicants will receive **CLAPA staff time** up to the value of the bursary to carry out the activities agreed.

CLAPA will lead on the activity and contact the applicants to advise how to progress the activity.

Useful Resources and Contacts

CLEFT (accepts funding applications for up to £50,000) <https://www.cleft.org.uk/>

Cleft and Craniofacial Clinical Studies Group (CSG) – Sarah Kilcoyne,
Sarah.Kilcoyne@ouh.nhs.uk

Early Career Researchers Group (ECRG) – Sophie Butterworth,
sophie.butterworth2@nhs.net

National Institute for Health and Care Research (NIHR) - <https://www.nihr.ac.uk/>

Research Capability Funding - <https://www.nihr.ac.uk/researchers/research-capability-funding.htm>

Professional Bodies e.g.

- Royal College of Speech and Language Therapists (RCSLT) - <https://www.rcslt.org/>
- Royal College of Surgeon's (RCSENG) - <https://www.rcseng.ac.uk/>
 - Includes Orthodontics/Dentistry