

Story and Photo Consent Policy



Last Updated: December 2021

Next Review: December 2023

Responsible: Impact & Influence Manager

This policy explains how CLAPA collects and uses photos, stories, case studies and interviews from the cleft community. It covers the principles we follow when publishing photos and telling stories, and lays out how we keep the subjects safe.

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1. Purpose

CLAPA is committed to sharing a wide variety of real, relatable stories and photos submitted by the cleft community on our website, social channels, and in other publicity. The cleft community trust us to use these stories and photos with the respect and care they deserve. This policy ensures any CLAPA staff involved with sourcing, creating, publishing or managing stories and photos do so appropriately.

2. Scope

This policy applies to all photos, videos, articles, posts and other pieces of media which feature an individual or group of individual affected by cleft lip and palate. It does not apply to anonymous quotes or non-identifiable images (such as of a group where individual faces are not clearly visible).

If there is ever doubt as to whether this policy applies to a piece of media, the wishes and privacy of the subject(s) remain the most important consideration. As such, staff should err on the side of applying this policy even when it's unclear if it applies.

3. Legal Framework

This policy sits alongside CLAPA's general data protection and safeguarding policies to provide protection to the people who access and contribute to our work.

4. Definitions

“Stories”

Articles, social media posts, videos or other pieces of media which focus on the personal experiences of an individual (or small group of individuals) affected by cleft lip and palate. These include photographs of people born with a cleft which are captioned with information about the subject, such as in CLAPA’s ‘Before and After Surgery’ photo gallery or in ‘Share A Smile’ social media posts.

“Photos”

Images and/or videos of people from the cleft community that are presented without commentary on who the subject(s) are. Examples include photos, screenshots or videos from a CLAPA event.

“Subject(s)”

In reference to stories, this is the person affected by cleft who is submitting, writing or otherwise providing the content for the story, as well as those mentioned in the story themselves. A subject is someone with a large ‘stake’ in the story in question who is able to give or revoke consent for it to be shared. For example, if a parent/carer submits a story about their child’s diagnosis, birth and surgery, both they and their child would be considered subjects of the story. If an adult submits a story in which they mention their parents (not by name), but the story centres on their own experiences, the adult would be the sole subject.

In reference to photos, this is anyone whose face (or other clearly identifiable features such as a tattoo) appears in the photo, screenshot or video.

Where there is disagreement about whether someone is the subject of a story or photo and can therefore request it be edited or removed, staff should err on the side of honouring any requests that help people feel more comfortable about what is being shared.

5. Responsibility

The Impact and Influence Manager has overall responsibility for ensuring this policy is adhered to. The Communications Officer is responsible for the day-to-day enforcement of this policy.

All staff involved with sourcing, collecting or managing stories and photos are responsible for doing so with this policy in mind.

6. Policy Principles

This section lays out key principles and considerations for all of CLAPA's work around collecting and publishing stories and photos.

6.1. Purpose

CLAPA collects and publishes photos and stories for the following purposes:

- Promoting a sense of community and connection amongst people affected by cleft lip and palate
- Raising awareness of cleft lip and palate to the general public
- To help people take ownership of their own experiences with cleft by telling their story
- Giving the cleft community access to a range of different experiences around cleft lip and palate to reduce isolation and promote positivity and optimism
- Demonstrating the impact that support services (such as CLAPA's) can have on someone's experiences. This is primarily intended to promote support services, but can also be used for fundraising.

We do not publish photos or stories which:

- Sensationalise or evoke pity for people affected by cleft
- Aim to shock the general public
- Shame or criticise those with different views or experiences

6.2. Safety

In the course of reviewing submissions, conducting interviews, or in correspondence with subject(s), CLAPA staff may be alerted to a safeguarding concern. These should be immediately raised with CLAPA's Safeguarding Team who can take the appropriate next steps.

6.3. Consent

Informed, written consent must be obtained. There is further guidance in CLAPA's Data Protection Policy, but the key points for informed consent in this case are:

- Knowledge of where media may be posted
- Knowledge of what it will be used for
- Knowledge of how to withdraw consent, and the limits of this in case of stories and photos which have been published online
- Any other considerations which the subject(s) may reasonably wish to know before their story or photo is published

6.3.1. Under 18s

Where the subject is under 18, CLAPA will take steps to ensure the dignity and privacy of the subject remains paramount. These include:

- Where parents or carers are submitting a story where their child aged 8 or older is the subject, they are asked to explain to their child what is being posted and where, and to respect their child's decision if they wish to revoke consent either at that point or in the future.
- If under 18s submit a story, their parent/carer will be contacted separately to verify that they consent to their child sharing their story in this way.

6.4. Privacy

Media should be edited and/or censored to preserve the privacy of subject(s), particularly those under the age of 18. This may include:

- Removing full names (particularly of children).
- Removing or censoring names of schools/nurseries, dates of birth and other identifying details unless these are considered central to the story, for example:
 - A fundraising story about a school may include the school name
 - A story about a child being born on a particular day, e.g. Christmas, World Smile Day
- Blurring or otherwise censoring the faces of people who are not subjects of the story, such as childhood friends in photos.

Unedited versions of stories and photos submitted will be stored in line with data protection regulations on CLAPA's secure server. These should not be shared outside of CLAPA with the exception of any concerns about a person safety or wellbeing as decided by CLAPA's Safeguarding Lead.

6.5. Dignity

The dignity and wellbeing of the subject(s) of the story must remain paramount. This is especially crucial where photos and other personal details of under-18s are submitted by parents/carers. Staff should use their best judgement and any concerns or hesitations around this should be discussed by the Communications Team and, where appropriate, with the Safeguarding Team.

Examples where there may be a concern include:

- Photos of babies and children which feature nudity or anything else which is likely to cause embarrassment (these should be cropped and/or excluded).

- Excessive or sensationalised discussions of difficulties children and young people may have gone through, such as bullying or other emotional distress.
- Discussions of cleft and the cleft care pathway which are sensationalist, dehumanising, or otherwise do not fit with our 'writing with respect' guidelines below.

6.6. Respect

CLAPA's Language Guide lays out further guidance for writing, editing and presenting stories appropriately. This guide should be read in full by anyone looking to write up an interview, in particular the following section on 'Writing with Respect':

- When writing about people affected by cleft, and particularly about people born with a cleft, staff should take care not to sensationalise cleft or the ways in which it may affect someone's life, and to humanise the subjects of any case studies used. While CLAPA as a charity must make a case for its work by highlighting the needs of our stakeholders, there are ways to do this effectively without patronising or infantilising people affected by cleft.
- Avoid evoking pity for the subject, and never suggest that the audience's inaction will cause harm to a particular individual (e.g. "Without your help, this expectant parent will have no one to talk to.")
- Avoid overly patronising phrases about how someone's personality or another quality is more important than their appearance (e.g. "It's what on the inside that counts"), as this is typically uncalled for and assumptive of an individual's values and views of cleft.
- Readers should never be asked to express an opinion on someone's appearance (e.g. "Like this post if you think [name] is beautiful"), and a particular person born with a cleft should never be used to 'prove a point' (e.g. "The media doesn't believe people with scars are beautiful, but look at [name]!").

7. Sourcing of Stories

This section covers the different ways in which stories are sourced, and what should be considered for each of these sources to ensure the wellbeing of the subjects.

7.1. Collected

Collected photos are taken by staff and volunteers at CLAPA events. A waiver must be completed as part of the event sign-up process. This waiver should explain that photos will be taken at the event, and explain how attendees can opt-out on the day.

A separate waiver should be signed for each event an individual attends – these are non-transferrable.

Unless separate explicit consent is sought for this, individuals should never be identified in the captions or narrative when these photos are shared.

Key considerations:

- It should be made clear at the start of the event when and how photos will be taken and how attendees can opt out. E.G. by turning off their camera, or by making themselves known to the photographer.
- Where possible, attendees should be warned in advance when photos are being taken so they have an opportunity to opt out.
- Photos should only ever be taken by CLAPA staff and/or volunteers on CLAPA's own equipment. Where professionals are involved, they may use their own equipment with appropriate safeguarding measures in place.
- At large events, it may be helpful to ask to take a 'reference' photo of any individuals who have opted out of appearing in photos so staff can ensure these individuals are removed from any wide or group shots.

7.2. Submitted

Submitted stories are volunteered by the subject and/or their family and sent through the ['Share Your Photo or Story'](#) form. This form gathers informed consent about where and how the story and/or photo will be shared and what can be done if someone changes their mind.

Key considerations:

- The content of these forms should be reviewed along with this policy to ensure they accurately reflect the reality of how these stories and photos are posted. They should also be updated whenever changes are made to how we use or store stories.
- The submitter should be contacted prior to the story being published to inform them of when this will be. This should be done in an email in direct reply to the story they have submitted, as this will give them a final chance to reconsider the content they sent and ask for any final alterations or withdraw consent.
- A clear record of each submission must be kept to allow individuals to easily withdraw consent in the future, and to assist with any complaints over breach of consent.

7.3. Referred

A referral comes from a CLAPA staff member outside the Communications Team who is already in contact with a potential subject and believes there is a strong story that they are willing to tell. In this case, the individual is assumed to be 'warm' to CLAPA and the staff member has judged that this referral is appropriate given their situation.

Key considerations:

- The subject(s) should not be actively receiving direct support from CLAPA (e.g. through the Parent Support Service) when they are referred to share their story. A referral should only come once support is concluded and then only if the staff member making the referral strongly believes this to be an appropriate action.
- The staff member making the referral must have discussed this with the subject beforehand and in terms which make it clear this is optional and will have no bearing on any further support they may wish to seek.
- If the staff member believes the subject wishes to submit their own photo or story, they may pass on a link to the Share Your Story or Photo form directly.
- If an interview is being considered, the staff member should refer the subject to the Communications Team. To ensure a written record is kept, the staff member should make the referral by emailing the subject with a member of the Communications Team copied in. This should include (where possible and appropriate) the previous discussion about the possibility of a story being published, though care should be taken to remove previous emails or pieces of text which would be considered confidential or which the subject may not be comfortable being passed on to another team member.

7.4. Requested

Requested stories are when a member of the Communications Team contacts an individual after coming to believe there is a strong story to tell. For example, after reading that individual's post on social media. While this individual will already have some contact with CLAPA, this is more of a 'cold' contact.

Key considerations:

- The request should be made privately to avoid any public pressure on the individual. It should be made through the same platform as the story was posted/shared to avoid people feeling 'spied on'.

- Any requests should come from an official CLAPA account, but the message should be signed with the name of the staff member who will be carrying forward this request.
- The staff member should use their best judgement to decide whether this person is ready to share their story through CLAPA, and to not make the request if there is any doubt. The individual's wellbeing must always be prioritised above getting a 'good' story.
- In the request, it should be made clear that this is optional, that there are different ways to share this story (including anonymously if appropriate), and that this will have no impact on any future support they may seek from CLAPA.
- Follow-up messages to 'chase' a response should never be sent. Every care should be taken to ensure no one ever feels under pressure to share their story.

7.5. Volunteers

Where volunteers have long-term involvement with CLAPA and regularly appear in, submit or create content for CLAPA, it may be appropriate to collect consent once for all future content they may appear in as part of this work.

This will apply to volunteers who are considered close enough to CLAPA to decide when and how to participate in content, and who feel able to revoke or change the consent they've given at any time. For example, the members of the Children and Young People's Council.

Key Considerations

- The consent should be collected using CLAPA's Photo Consent Form. There should also be a written record of the staff member explaining what the consent is for and how it can be changed or revoked.
- Although this consent only needs to be collected once, staff should still briefly explain to volunteers the nature of the content they're creating and how it will be used every time, especially if it is different in any significant way. This explanation should include a reminder that they can opt-out at any time.
- For volunteers under 18, staff should take particular care to ensure they are fully comfortable with what they are consenting to, and understand that they can change their mind at any time, including revoking consent for existing media they appear in.

8. Interviews

This section concerns interviews where a CLAPA staff member asks questions of a story subject, and then writes this up afterwards. These can be done in person, over video calls, or over the phone.

8.1. Arranging Interviews

Interviews over video call (preferred) or phone should be arranged at a time to suit the subject(s). The interviewer should be up front and transparent about the topic and purpose of the interview, and should send over questions in advance where possible.

8.1.1. All subjects

All subjects should be made aware that:

- They can request before, during or after the interview that any particular topics or comments made during the interview not be included in the final publication.
- They will be sent the text (and/or a draft video where appropriate) before publication so they can approve the contents.
- They are free to stop the interview at any time, either to be picked up later or to withdraw completely, and that this will have no bearing on any support they (and/or their child) may receive from CLAPA in the future or their future cleft care.
- This interview is to create a case study for publicity purposes to help CLAPA build a cleft community, raise awareness of cleft lip and palate, and promote our work. CLAPA staff are not medically trained, and cannot provide advice or any kind of formal support as part of this interview process.
- As part of our commitment to safeguarding, there may be times when we have a responsibility to report concerns to local safeguarding bodies or authorities like the police, however we would always explain this first, unless by doing so we were putting an individual at risk of harm.

8.1.2. Under 18s

- Consent of parents/carers should be sought prior to any interviews being arranged.
- The usual rules for online events with under 18 apply, including:
 - Two staff being present, one of which will ideally be the CYP Coordinator, but where this is not possible, at least one staff member must have an appropriate disclosure check.
 - The meeting being recorded
 - A parent/guardian either present or available to 'drop off' the young person, with an exception for the CYPC where there is general activity consent.
- If the interview takes place over the phone, the parent/guardian's phone and/or a landline should be used unless the parent/guardian has asked for the young person's phone to be used. The parent/guardian should be spoken to first to confirm the details of the interview, and asked to switch their phone to 'speakerphone' so they are aware of what the staff member is saying. The staff member should use a CLAPA mobile phone

and record the call in a secure manner, though how they do this will depend on the model of phone.

- Extra care must be taken to ensure the comfort, dignity and wellbeing of the young person at all times. Staff should be extra-aware of any signs of discomfort or reluctance to respond, and act appropriately to reassure the young person they do not need to answer and move on. Staff should be prepared to halt the interview when necessary.
- Staff are responsible for ensuring their Safeguarding knowledge is up to date. This includes re-reading the ['Recognising a Concern'](#) document prior to the interview.

8.2. Written interviews

- Subject(s) should be sent a copy of their interview to view in advance of it being posted. They should be invited to make any comments or ask any questions to ensure they are happy with what will be shared.
- Subject(s) should be contacted after their story is 'live' with links to their story on our website and/on social media.
- Subject(s) must be aware that they can retract their story, or parts of it, at any time in the future, but should be aware that by this time members of the community and public may have already shared their story and/or photos online.

9. Writing and Editing Stories

Submissions may be edited for spelling, grammar and clarity, but every effort should be taken to maintain the subject(s) tone and voice.

Where sections of a case study are not usable without significant edits, editors should seek clarification on the meaning and/or approval on these edits. If this cannot be obtained for whatever reason, these sections should be removed rather than edited into something unrecognisable.

Filler words (e.g. 'um') should not be included in transcriptions or quotes unless they are crucial to the meaning and/or tone of the story.

The subject(s) of the case study should have final approval before any interviews or write-ups are posted.

10. Retention and Removal

Once they are published, stories and photos will be used by CLAPA for a period of five years unless consent is revoked or the story is removed before that time.

After five years, the stories will be 'phased out' of publication on the CLAPA website and archived on CLAPA's servers for a further two years, after which they'll be deleted. By 'phased out', we mean that these stories will be replaced by more recent images wherever possible.

Stories will not be removed from social media accounts unless there is a particular request from the subject or their parent/carer to do so. This is because it will be long enough ago in the past that it's unlikely to re-surface or cause concern or discomfort to the subject.

If the stories are of particularly high quality and/or are frequently used, CLAPA may contact the subject or their parent/carer to ask for renewed consent to continue to actively use their story. If we do not hear back, we will consider consent to be revoked and phase out the stories as usual.

If the stories or photos were collected as part of long-term volunteering (see '7.5. Volunteers'), we would consider this 5-year period to start when the subjects stop their ongoing involvement with CLAPA as volunteers, the date of which would be on their contact record.

There may be other exceptions to this five-year period, such as informational videos, but these terms will be explained to any subjects at the point at which they consent to appearing in or submitting any media.

11. Monitoring and Review

This policy and the corresponding forms will be reviewed every two years. If there are issues or concerns raised about these in the meantime, they will be updated as necessary.

All staff are responsible for reporting any concerns they have (or see raised) about CLAPA's story policy or procedures.

12. Implementation

This policy will be implemented for all media collected from January 2022 onwards. As CLAPA has a great deal of existing content created and shared before then, a great deal of this content will not meet this policy's standards in terms of record retention. CLAPA will work to bring the media on our website and publicity materials (excluding e-newsletters and social media posts that have already been shared) into line with this policy, and the effort to do so will be well underway by the end of 2022.

13. Support for this Policy

To discuss this policy, contact CLAPA's Impact and Influence Manager Anna Martindale at anna.martindale@clapa.com. Concerns can also be raised with CLAPA's Safeguarding Team at safeguarding@clapa.com.

To raise anonymous concerns about this policy, staff can contact CLAPA CEO Claire Cunniffe (claire.cunniffe@clapa.com) in confidence. Volunteers and others in the wider community can use CLAPA's contact form anonymously (<https://www.clapa.com/contact-us/>).

14. Related Documents

- **CLAPA Data Protection and Record Retention Policies:** <T:\HR & OFFICE MANAGEMENT\POLICIES\COMMUNICATIONS & DATA\Data Protection & Photo Consent>
- **CLAPA Safeguarding Policies:** <T:\HR & OFFICE MANAGEMENT\POLICIES\SAFEGUARDING>
- **Share Your Story or Photo Form:** <https://clapa.formstack.com/forms/shareyourstory>
- **Photo Consent Form:** <https://clapa.formstack.com/forms/photoconsent>

Appendix 1

Which form and procedure to use for different kinds of media (including stories, photos, videos)

