



Guidance on our Social Media Policy (GoPI3Ks 1176289)

A comprehensive guide for social media use for GoPI3Ks's channels and for individuals using social media in a personal capacity as a representative of GoPI3Ks.

This policy will be reviewed annually. GoPI3Ks will amend this policy, following consultations with our trustees where appropriate and make any amendments needed.

This policy is intended for all staff and volunteers of the charity; this includes *[trustees and volunteers]*. Before engaging in social media activity, you must read this policy, which contains guidance that will help you adhere to our standards.

Date of last review: August 2025

Introduction

What is social media?

Social media is the collective term given to web-based tools and applications which enable users to create, share and interact with content (words, images, graphics and video content), as well as network with each other through the sharing of information, opinions, knowledge and common interests. Examples of social media platforms include Facebook, X (formerly known as Twitter), LinkedIn, Instagram, YouTube, Twitch and TikTok.

Why do we use social media and what can we use it for?

Social media is essential to the success of communicating GoPI3Ks's work. It is important for us to participate in social media to engage with our audiences, whether this be the general public, those living with PROS or care givers/family/friends of those with PROS. It allows us to contribute to relevant conversations and raise the profile of GoPI3Ks. Some staff and volunteers may also support the charity's work using their personal accounts, and many will have social media accounts for personal use.

Building an engaged online community can lead to more significant long-term support and involvement from supporters. [Social media guidance from the Charity Commission](#) (September 2023) conveys how social media can be a highly effective way for a charity to engage its audiences and communicate about its work.

Social media helps us to:

- ☐ Promote our campaigns
- ☐ Share our news and updates with our audiences
- ☐ Celebrate our successes
- ☐ Raise awareness of important issues and challenges
- ☐ Support our fundraising activities
- ☐ Increase our membership
- ☐ Build an online supportive community
- ☐ Raise our public profile and strengthen our reputation
- ☐ React to quickly changing situations and topics, especially in the ever changing world of PROS research.

Why do we need a social media policy?

Social media is a fast-moving online world, where nuance and context can be easily lost. While social media brings the charity to a wide audience, it can also present risks. We want to ensure that all staff and volunteers using social media represent and reflect GoPI3Ks in the best way possible. It is also important to mitigate risks (such as reputational or legal issues) associated with the use of social media to protect our supporters, staff and volunteers, work and reputation.

While we encourage the use of social media to support our communications strategy or plans, we have important standards, outlined in this policy, which we require everyone to observe and adhere to. The difference between a personal and professional opinion can also be blurred on social media, particularly if you're discussing issues relating to GoPI3Ks's work. Publication and commentary on social media carries similar obligations and is subject to the same laws as other kinds of publication or commentary in the public domain.

Failure to comply with this policy could expose GoPI3Ks to reputational damage as well as putting staff, volunteers, services users and members at risk.

Responsibilities and breach of policy

Everyone is responsible for their compliance with this policy.

Participation in social media on behalf of GoPI3Ks is not a right but an opportunity, so it must be treated seriously and with respect.

Breaches of policy or inappropriate behaviour may incur disciplinary action, depending on the severity of the issue. Staff and volunteers who are unsure about whether something they propose to do on social media might breach policies should seek advice from our chairperson by emailing: gopi3ks@yahoo.com

Setting out the social media policy

Application

This policy applies to all social media platforms used by trustees and volunteers in a professional and personal capacity.

This policy also applies to online blogs, wikis, podcasts, forums, and messaging based apps, such as WhatsApp. Social media can be accessed in various ways, including from a desktop or laptop computer, tablet or smartphone. This policy applies to the use of all such devices.

Internet access and monitoring usage

There are currently no access restrictions to any of our social media sites. However, when using the internet at your place of work, please be mindful that this should not interfere with your paid work/employment and should be undertaken during any breaks and free time.

Point of contact for social media and authority to post on GoPI3Ks's social media accounts

Our Chairperson is responsible for the day-to-day publishing, monitoring and management of our social media channels. If you have questions about any aspect of these channels, please speak to the Chairperson. Other than our trustees, no volunteer is permitted to post content on GoPI3Ks's official channels without the permission of the Chairperson, who can be contacted at: gopi3ks@yahoo.com

Which social media channels do we use?

GoPI3Ks uses the following social media channels:

- Facebook: <https://www.facebook.com/groups/Gopi3ks/>
- X: <https://x.com/gopi3ks>
- Instagram: <https://www.instagram.com/gopi3ks/>

GoPI3Ks uses social media to inform audiences of relevant information pertaining to PROS, whether this be new research, drug trial information, information on doctors as well as various information on rare disease events that maybe of relevance to our audience. We also aim to engage and support those living with or affected by PROS, to offer the opportunity to apply for financial assistance, engage with others, help with fundraising and build an online community.

Policy ownership

The Chairperson is responsible for authoring and updating this document. The policy must be approved by the trustees and reviewed every year, unless a significant change requires the organisation to check the policy before the next review date. All staff and volunteers will be notified of updates.

Rules for use: headlines

Code of conduct headlines

- I will not insult, harass, bully or intimidate individuals or organisations
- I will respond to others' opinions respectfully and professionally
- I will not do anything that breaches my terms of a voluntary role
- I will acknowledge and correct mistakes promptly using provided guidance
- I will disclose conflicts of interest where I am able
- I will not knowingly post inaccurate information
- I will link to online references and original source materials directly
- I will be considerate, kind and fair
- I will always ensure my activity does no harm to the organisation or to others
- I will champion GoPI3Ks and its services

Rules for use: full list

Using GoPI3Ks's social media channels — appropriate conduct

1. Know our social media guardians

The Chairperson is responsible for setting up and managing GoPI3Ks's social media channels. The Chairperson has overall ownership of these accounts and only those authorised to do so by the Chairperson will have access to these accounts.

The Chairperson will uphold best practices for channel security with secure passwords that regularly change. Never give out the passwords for our channels without express permission from the Chairperson

2. Be an ambassador for our brand

Staff and volunteers must ensure they reflect GoPI3Ks values in what they post and use our tone of voice. Please note only the Chairperson and current trustees are permitted to respond to comments on our social media posts on behalf of the organisation. All posts and comments should be attributed to the charity and not an individual. In special cases it may be appropriate for a staff member or volunteer to make an individual comment as themselves, but this should be under the supervision, and with the approval, of the Chairperson.

3. Always pause and think before posting

When posting from GoPI3Ks's social media accounts, you must respond to comments in the voice of our charity and not allow your own personal opinions to influence responses. Volunteers must not reveal their personal opinions via our accounts by 'liking', 'sharing' or 'reposting' as GoPI3Ks, unless it is clear that you are doing so as an individual staff member or volunteer as part of an approach agreed with the Chairperson (e.g. as part of a 'takeover' of the charity's account). If you are in doubt about GoPI3Ks's position on a particular issue, please speak to the Chairperson:

gopi3ks@yahoo.com

4. Ensure brand consistency

Staff or volunteers must not create or manage any other social media channels, groups or pages on behalf of GoPI3Ks without express permission from the Chairperson and training. This is to ensure brand consistency for users and the appropriate safeguarding and monitoring processes are in place.

5. Remember the bigger picture and focus on the benefit

Staff and volunteers must make sure that all social media content has a purpose and a benefit for GoPI3Ks to further our charitable purposes. All content must accurately reflect GoPI3Ks's agreed position: To advance the education of the general public & those living with PROS by raising awareness, providing information & educational materials.

6. Bring value to our audience(s)

Those responsible for the management of our social media accounts should answer questions as swiftly as possible to help and engage with our service users and supporters.

7. Seek permission to share

If staff or volunteers outside of GoPI3Ks wish to contribute content for social media, whether non-paid for or paid for advertising, they should obtain guidance and permission from the Chairperson:

gopi3ks@yahoo.com

8. Obtain consent

Staff and volunteers must not post content about supporters, service users or partners without their, or their guardian's, express permission. If staff or and volunteers are sharing information about supporters, service users or third party organisations, this content should be clearly labelled so our audiences know it has not come directly from GoPI3Ks. If using interviews, videos or photos that clearly identify a child or young person, staff and volunteers must ensure they have the consent of a parent or guardian before using them on social media.

9. Put safety first

It can be challenging working on social media and there may be times where staff or volunteers could be subject to unpleasant or abusive comments directed at the charity, our work or people. We encourage everyone who is on social media on behalf of the charity to be aware of our safeguarding and wellbeing practices: <https://gopi3ks.com/privacy-safeguarding-policy> and consult with the Chairperson where necessary.

It is also vital that GoPI3Ks does not encourage others to risk their personal safety or that of others, to gather materials in pursuit of social media engagement. For example, a video of a stunt or visiting an unsafe location.

10. Stick to the law

Staff and volunteers must not encourage people to break the law to supply material for social media, such as using unauthorised video footage. All relevant rights for usage must be obtained before publishing material.

11. Remain politically neutral

GoPI3Ks is not associated with any political organisation or have any affiliation with or links to political parties. We can express views where appropriate on policies that impact our work and service users, but it is essential that GoPI3Ks remains, and is seen to be, politically neutral.

We cannot endorse a political party or candidate. We must carefully manage the risk that we are perceived to have any party-political bias and should carefully consider any posts which might be perceived as such, for example, posts which talk about individual politicians or parties rather than policies.

12. Check facts and be honest

Staff and volunteers should not automatically assume that material that's shared or included in any post is accurate and should take reasonable steps where necessary to seek verification – for example, by checking data/statistics and being wary of photo manipulation. If you've made a mistake, don't be afraid to admit it. But think first about how to manage any risk to the charity and its brand in doing so by consulting with the Chairperson to craft the response.

13. Seek advice for complaints

If a complaint is made on GoPI3Ks's social media channels, staff and volunteers should seek advice from the Chairperson before responding. If they are not available, then staff and volunteers should send an email to: gopi3ks@yahoo.com with a clear subject heading so that complaints are dealt with quickly.

14. Know what to do in a crisis

Sometimes issues can arise on social media which can escalate into a crisis situation because they are sensitive or risk serious damage to the charity's reputation.

The nature of social media means that complaints are visible and can escalate quickly. Not acting can be detrimental to the charity or our people. The Chairperson regularly monitors our social media spaces for mentions of GoPI3Ks so we can catch any issues or problems early. If there is an issue that could develop or has already developed into a crisis situation, the Chairperson will do the following: follow our guidance on dealing with a serious incident &/or follow:

<https://www.gov.uk/guidance/how-to-report-a-serious-incident-in-your-charity>

If any staff or volunteers outside of the GoPI3Ks team becomes aware of any comments online that they think have the potential to escalate into a crisis, whether on GoPI3Ks's social media channels or elsewhere, they should speak to the Chairperson immediately. It is the responsibility of all staff and volunteers to report complaints or comments that could escalate into a crisis or have serious implications for the charity. Only the Chairperson is permitted to amend or delete content in a crisis.

See further guidance from CharityComms regarding [crisis communications and best practice](#).

15. Timings, schedules and rotas

Our social media channels are monitored Monday to Friday with active hours of 9am-6pm. The weekend or public holidays this will be less with sporadic monitoring of the social media channels,

16. Use AI appropriately

AI can be a valuable tool that can support our communications activities. However, staff and volunteers must seek permission from the Chairperson before using AI and only use approved AI tools and processes.

17. Handover ownership if your role changes

You must hand over ownership of the group/page/account you manage to another appropriate staff member (or volunteer) if you change roles or if you leave GoPI3Ks.

Use of personal social media accounts — appropriate conduct

Personal social media use by staff and volunteers can sometimes be attributed to the charity or bring other risks for the charity or individual staff or volunteers. This policy does not intend to inhibit personal use of social media, but instead flags up those areas in which risks or conflicts might arise. GoPI3Ks staff and volunteers are expected to behave appropriately, and in ways that are considerate of GoPI3Ks's values and policies, both online and in real life.

1. Separate your personal views

Be aware that any information you make public could affect how people perceive GoPI3Ks. You must make it clear when you are speaking for yourself and not on behalf of GoPI3Ks. If you are using your personal social media accounts to promote and talk about GoPI3Ks's work, you must use a disclaimer such as: "Views are my own" or "The views expressed on this site are my own and don't necessarily represent GoPI3Ks's positions, policies or opinions."

2. Take care when publishing personal views (particularly trustees and senior staff)

Those in senior management including trustees and public-facing or specialist roles where they are well known in their field of expertise, must take particular care as personal views published may be misunderstood as expressing GoPI3Ks's view.

For senior roles, we expect you to take additional steps, such as:

- Being aware of your duties and responsibilities.
- Avoiding posting any material which might be construed as contrary or conflicting with to the charity's charitable mission or work.

3. Discuss risks and conflicts of interest

Staff and trustees who have a personal blog, social media profile or website which indicates in any way that they work/volunteer at GoPI3Ks should discuss any potential risk or conflicts of interest with the Chairperson. Similarly, staff or trustees who want to start blogging and wish to say that they volunteer for GoPI3Ks should discuss any potential risk or conflicts of interest with the Chairperson.

4. Protect your personal reputation

Think about your personal reputation as well as the charity's. Express your opinions and deal with differences of opinion respectfully. Don't insult people or treat them badly. Passionate discussions and debates are fine, but you should always be respectful of others and their opinions. Be the first to correct your own mistakes.

Remember that if you have a public profile with the charity, your personal social media accounts could be looked at by critics of the charity, and bear this in mind when posting.

5. Use your common sense and good judgement

Be aware of your association with GoPI3Ks and ensure your profile and related content is consistent with how you wish to present yourself to *the general public, PROS community and funders*.

6. Refer press enquiries

If a staff member or volunteer is contacted by the press about their social media posts that relate to GoPI3Ks, they should talk to the Chairperson immediately and under no circumstances respond directly.

8. Keep your political activity separate from the charity

When representing GoPI3Ks, volunteers are expected to uphold GoPI3Ks's positioning of keeping their views separate from the charity. Volunteers who are politically active in their spare time need to be clear in separating their personal political identity from GoPI3Ks and understand and avoid potential risks and conflicts of interest. Staff should also inform the Chairperson about any such political activity. As set out in point two above, senior staff and trustees should take particular care.

9. Protect your privacy

Be careful with your privacy online and be cautious when sharing personal information. Remember that a simple 'like' can draw attention to your personal accounts. What you publish is widely accessible and could be around for a long time, so do consider the content, and your privacy, carefully.

All staff and volunteers who wish to engage with any of GoPI3Ks's social media platforms are strongly advised to ensure that they set the privacy levels of their personal sites as strictly as they can and to opt out of public listings on social networking sites to protect their own privacy. All volunteers should keep their passwords confidential and change them often.

In their own interests, volunteers should be aware of the dangers of putting personal information onto social networking sites, such as addresses, home and mobile phone numbers.

10. Help us to raise our profile (where appropriate)

We encourage staff and volunteers to share posts that we have issued. When online in a personal capacity, you might also see opportunities to comment on or support GoPI3Ks and the work we do. Where appropriate and using the guidelines within this policy (and taking into consideration the information above), we encourage staff and volunteers to do this as it helps users connect to us and raises our profile.

However, please take care to think about the reputation of the charity. If your personal social media account is not professional or otherwise appropriate for our audiences, please do not use it to amplify or promote the charity, as to do so brings risks both to you personally and to the charity. Similarly, if the content is controversial or misrepresented, please highlight this to the Chairperson who will respond as appropriate.

11. Avoid logos or trademarks

Never use GoPI3Ks's logos or trademarks unless approved to do so. Permission to use logos must be requested from the Chairperson and any content created must adhere to our brand guidelines. If permission is granted, content must be approved by the Chairperson before publishing.

12. Staying safe online

It can be challenging working on social media and there may be times where volunteers could be subject to unpleasant or abusive comments directed at the charity, our work or people. We encourage everyone who is on social media to be aware of our safeguarding and wellbeing practices to deal with online abuse and consult with the Chairperson where necessary.

Volunteers should be vigilant regarding suspicious content or links and must not reveal personal, confidential or sensitive information about themselves, other volunteers or supporters of GoPI3Ks. Volunteers should be wary of fake accounts that may claim to be GoPI3Ks and should immediately notify the Chairperson.

Care must also be taken to ensure that any links to external sites from our social media accounts are appropriate and safe. For more information, please see our data protection policy:

<https://gopi3ks.com/privacy-safeguarding-policy>

Further guidelines: using social media in a professional and personal capacity

Defamation

Defamation is when a false statement that is damaging to a person's reputation is published in print (such as in media publications) or online (such as Instagram Story, Facebook Live, Snapchat post). Whether staff or volunteers are posting content on social media as part of their job or in a personal capacity, they should not bring GoPI3Ks into disrepute by making defamatory comments about individuals or other organisations or groups.

Copyright law

It is critical that all staff or volunteers abide by [the laws governing copyright](#), under the Copyright, Designs and Patents Act 1988, when representing the charity. Never use or adapt someone else's images or written content without permission. Failing to acknowledge the source/author/resource citation, where permission has been given to reproduce content, is also considered a breach of copyright.

Confidentiality

Any communications that staff and volunteers make must not breach confidentiality. For example, information meant for internal use only or information that GoPI3Ks is not ready to disclose yet. For example, a news story that is embargoed for a particular date, or information from people who the charity has worked with which is private. Please refer to our: <https://gopi3ks.com/privacy-safeguarding-policy>

Discrimination and harassment

Staff and volunteers should not post content that could be considered discriminatory against, or bullying or harassment of, any individual, on either an official GoPI3Ks social media channel or a personal account. For example:

- Making offensive or derogatory comments relating to sex, gender, race, disability, sexual orientation, age, religion or belief.
- Using social media to bully another individual.
- Posting images that are discriminatory or offensive or links to such content.

Accessibility

In line with GoPI3Ks equity, diversity and inclusion views, we endeavour to ensure our social media is as accessible as possible. This includes:

- Using plain English, accessible fonts and avoiding small text sizes

- Using contrasting colours
- Using subtitles where appropriate
- Using alt text for videos and images
- Explaining text contained in an image in the copy that accompanies it

You can view more guidance on the government website: [planning, creative and publishing accessible social media campaigns](#).

For accessibility best practices, visit the CharityComms resource: [Accessible communication - a starting point to foster more inclusive comms](#).

The Lobbying Act

Charities are legally allowed to campaign to bring about a change in policy or law to further their organisational purpose but can never be party political. In most cases, spending on charity campaigns that are in accordance with charity law will not be regulated under electoral law (often known as the 'Lobbying Act').

Under the Lobbying Act, organisations (including charities which spend more than £10,000 across the UK on 'regulated activity' during the regulated period need to register with [the Electoral Commission](#) within the outlined windows for elections.

Regulated activity is any activity which could reasonably be seen as intended to influence people's voting choice, either for parties or candidates (which a charity could never do) or for categories of candidates (e.g. female candidates, or candidates who support Net Zero). During these periods, all campaigning activity will be reviewed by the Chairperson.

Use of social media to support fundraising activities

Our social media platforms play a key role in our fundraising efforts and engaging with our donors. Before using our social media channels for fundraising purposes, staff and volunteers adhere to [The Code of Fundraising Practices](#).

Protection and intervention

The responsibility for measures of protection and intervention lies first with the social networking site itself. Different social networking sites offer different models of interventions in different areas. For more information, refer to the guidance available on the social networking site itself. For example, Facebook. However, if a staff member or volunteer considers that a person/people is/are at risk of harm, they should report this to the Chairperson immediately.

Under 18s and vulnerable people

Young and vulnerable people face risks when using social networking sites. They may be at risk of being bullied, publishing sensitive and personal information on their profiles, or from becoming targets for online grooming or radicalisation. Where known, when communicating with vulnerable or young people under 18-years-old via social media, staff and volunteers should ensure the online relationship with GoPI3Ks follows the same rules as offline.

Staff and volunteers should be aware that children under the age of 13 should not be encouraged to create their own personal social media accounts or engage with others and are not legally allowed to use social media channels such as Facebook, Instagram or X.

Staff and volunteers should ensure that vulnerable and young people have been made aware of the risks of communicating and sharing information online, and given guidance on security and privacy settings as necessary. Staff and volunteers should also ensure that the site itself is suitable for the vulnerable or young person and GoPI3Ks content and other content is appropriate for them. Please refer to our policy: <https://gopi3ks.com/privacy-safeguarding-policy>

All staff members and volunteers have a responsibility to do everything possible to ensure that vulnerable and young people are kept safe from harm. If you come across anything online that could mean someone is at risk, you should follow GoPI3Ks's safeguarding policies.

[The Online Safety Act 2023](#) has introduced measures to ensure children are protected online.

Engaging on emotive topics

GoPI3Ks may be involved in issues that provoke strong emotions. The emotive content we share via our social media channels can engage our audiences and help us achieve our communications goals. However, it is important to plan appropriately and consider potential reputational risks to the charity. For more information, visit [the government resource called charities and social media](#).

Public Interest Disclosure

Under [the Public Interest Disclosure Act 1998](#), if a staff member releases information through GoPI3Ks's social media channels that is considered to be in the interest of the public, GoPI3Ks's "guidance on how to report a serious incident" must be initiated before any further action is taken.

Please note: While all attempts have been made to cover an extensive range of situations, it is possible that this policy may not cover all eventualities. There may be times when professional judgements are made in situations not covered by this document, or which directly contravene the standards outlined in this document.

It is expected that in these circumstances staff will always consult with the Chairperson where possible or advise the team of the justification for any such action already taken or proposed.

Related policies, laws and guidance

- Confidentiality Policy: <https://gopi3ks.com/privacy-safeguarding-policy>
- Code of Conduct Policy: <https://gopi3ks.com/privacy-safeguarding-policy>
- Safeguarding Children and Young People Policy: <https://gopi3ks.com/privacy-safeguarding-policy>
- Safeguarding Adults at Risk Policy: <https://gopi3ks.com/privacy-safeguarding-policy>
- Complaints, Compliments and Feedback Policy: <https://gopi3ks.com/privacy-safeguarding-policy>
- Reporting [serious incidents](#) to the Commission, police or other regulators
- Staff wellbeing and safeguarding procedures: <https://gopi3ks.com/privacy-safeguarding-policy>

Further external guidance

- [The Charity Commission guidance for charities on social media](#)
- [The Charity Commission checklist for developing a social media policy](#)
- [National Cyber Security Centre's guidance on social media and how to use it safely](#)
- [National Cyber Security Centre's guidance on protecting your published content](#)
- [The Charity Commission guidance on campaigning and political activity guidance for charities](#)
- [Government guidance on the Online Safety Bill](#)
- [Bates Wells website](#)

GoPI3Ks Social Media Policy Agreement

Staff Agreement

I have read and understood the GoPI3Ks social media policy. I agree to abide by the rules set out in this policy and I understand that failing to abide by this policy may result in disciplinary action.

Name: Mandy Sellars

Role: Chairperson

Signed: M. Sellars

Date: 01/08/2025