

Data protection and support groups: Frequently Asked Questions

As a SGO (Support Group Organiser) you will have access to the personal data of people who come to the support group, as well as that of other Lymphoma Action volunteers and members of staff.

As part of your Volunteer Agreement, you have signed a Confidentiality and Data Protection Agreement, saying that you will follow Lymphoma Action's policy and processes for data protection. However, we don't want SGOs to be unduly worried about data protection: you just need to follow the instructions and guidance we give you, ask if you don't understand anything and let us know straightaway if something goes wrong.

Frequently asked questions

This set of frequently asked questions (FAQs) is one of the resources mentioned in the [Support Group Organisers' guide](#) and is designed to supplement the guide and your volunteer induction and training, to help you understand data protection and apply the policy and processes at the support group.

These FAQs are not exhaustive, so if you have questions that are not addressed here or need more information about these ones, please contact your staff contact or the Volunteering Development Manager. We will add new questions and answers as we get them and as changes are made.

The FAQs are divided into subject areas to help you find the answers you're looking for:

- **What is personal data?**
- **What is data protection and why does it matter?**
- **What is my role as an SGO in relation to personal data?**
- **What is the difference between data protection and confidentiality?**
- **What should I do if I think data security has been breached?**
- **Registering people at the support group**
- **How do SGOs safely 'process' personal data?**
- **Personal data and relationships at the support group**
- **Social events outside support group meetings**
- **Support group speaker contact details**

What is personal data?

Personal data covers any information that can identify a living individual and includes their name, address, email and phone numbers, date of birth and any other information that could lead to them being identified – either on its own or in combination.

Some personal data comes into a **special category** because it is very sensitive. It includes any information about physical or mental health, including whether someone is affected by lymphoma. So, just the fact of someone attending a Lymphoma Action support group is special category personal data because anyone would know something about their health status from knowing this.

Other special categories of personal data are racial or ethnic origin, sexual orientation, political opinions, religious or philosophical beliefs, trade union membership, sex life, genetic data and biometric data obtained as means of identifying someone.

What is data protection and why does it matter?

You have probably heard news stories about personal data being misused, including by some charities. To give greater protection to everyone's personal data, the GDPR (General Data Protection Regulation) was introduced in 2018 and is part of UK law. It gives everyone greater rights to decide who holds their personal information and how it is used, as well as greater ability to access it and have redress for infringements.

GDPR also places greater requirements on 'data controllers' (people and organisations that obtain and use personal data, including Lymphoma Action) to reduce the use of personal data and prevent breaches of data security. Data controllers have a legal duty to have certain policies and documents in place that cover all the ways in which personal data is handled or 'processed'.

GDPR also substantially increases the penalties for breaches to levels that have serious implications for data controllers that get things wrong.

For the security of everyone concerned and to protect the reputation and continued ability of Lymphoma Action to inform, support and connect people affected by lymphoma, it is essential that volunteers follow the instructions given about data protection. If in doubt, always ask your staff contact.

What is my role as an SGO in relation to personal data?

Under the GDPR, all SGOs are classified as 'authorised persons of Lymphoma Action'. 'Authorised person' is the technical term in the GDPR for someone who is part of an organisation and who uses personal data obtained by that organisation in their role.

By signing the Confidentiality and Data Protection part of your Volunteer Agreement, you become someone who is authorised to handle limited personal data in compliance with the instructions given to you by the charity. In return, Lymphoma Action provides protection from SGOs having personal liability for any data breaches you make in good faith, for example, by making a mistake or misunderstanding the charity's instructions or guidance.

We don't want you to be worried about data protection, important though it is. SGOs just need to follow the instructions given to you – ask, if you don't understand something - and let us know straightaway if something goes wrong, so we can put it right.

What is the difference between data protection and confidentiality?

There is a crossover between data protection and confidentiality - they are both about the personal data and privacy of individuals, so the content can be the same. For practical purposes, the difference lies in how a person's information is obtained and treated.

Data protection covers personal data obtained in a few legally defined ways, which is then stored, digitally or on paper, to be used only in ways the individual whose data it is knows about and has agreed to. For SGOs, that means the name and contact details on the Support Group Registration Form and the fact the person attends a health-related service. SGOs have a duty under your Volunteering Agreement to keep this information secure and never give it to anyone else (or any other organisation) outside of Lymphoma Action (see under *What is my role as an SGO in relation to personal data?*).

For SGOs, **confidentiality** covers this personal data *and* any additional personal information that an attendee discloses to you in your volunteering role or at a support group meeting. This information is never written down or stored anywhere and isn't used for any purpose other than to support the person at that time.

Attendees may only feel able to talk openly about their experience of lymphoma because they trust that the SGOs (and other attendees) won't disclose their information to anyone else or discuss it outside of the meeting room. In other words, it will be treated as confidential. This is why we ask SGOs to remind/explain confidentiality at the start of each support group meeting.

Further information about confidentiality in volunteering and at the support group is covered in the separate resource **Confidentiality**.

What should I do if I think data security has been breached?

Q1 What is a data security breach?

A1 Data security is breached when a person or organisation that is not entitled to do so obtains, stores, uses, shares or deletes personal data. 'Processing' is the technical shorthand term for doing any of those things – really, any action at all in relation to personal data. A data breach also covers the misuse of data that has been lawfully obtained and stored.

A data breach can happen in many ways, including accidentally or deliberately sending it to another person or organisation or them deliberately obtaining the data, for example by hacking into a computer. Breaches from misuse are often using data in ways the person whose data it is has not been told about beforehand or that they haven't consented to or that defies their stated wishes.

Q2 How could an SGO breach data security?

A2 Currently, the most likely way is forgetting to 'Bcc' support group attendees when sending emails, which means that they can all see, and use, each other's personal data. Other ways to be aware of include:

- giving contact details of one attendee to another who is organising a social get-together for people at the support group (see under *Social events outside support group meetings*)
- including a speaker's personal details in an email to attendees (see under *Support group speaker contact details*)
- leaving a list of attendees' names and contact details in the meeting room at the support group venue or on public transport or in your car, which is then broken into...
- storing a list of attendees' names and contact details on your laptop or tablet, which is then accessed by your partner or child
- giving a register of attendees to the support group venue (see 'What if the meeting venue wants a list of attendees?' under *How do SGOs safely 'process' personal data?*)
- not updating or renewing your online security, allowing your device to be hacked and the personal data stolen
- not setting a password on your phone or tablet, which has attendees' contact details stored on it, allowing others to access it.

Q3 What should I do to avoid a data breach?

A3 Follow the instructions and guidance provided to you by Lymphoma Action in the course of your induction, training and volunteering. As a general guide, take the following precautions, depending on how you store and use the personal data.

- **Electronic devices** There are general cyber security actions that everyone should take to protect their own personal data and devices from hacking and fraud, which would also protect the personal data of Lymphoma Action service users, volunteers and staff members, stored on them.
 - These include setting a password, having adequate security programmes installed on each device and keeping these updated.
 - You must also delete all personal data from your electronic devices when asked to do this by Lymphoma Action (see **Q6** 'When should I delete or destroy personal data?' and **Q7** 'How should I delete or destroy personal data?' under *How do SGOs safely 'process' personal data?*).
 - Don't share devices with others and/or keep personal data for Lymphoma Action in password protected accounts that sharers don't have access to.
 - If you need advice about any of this, you will usually need to consult the support desk of your device or service provider but do ask your staff contact, as the charity's digital team might be able to answer your question or explain what is required.
- **Paper systems** Most SGOs will need to store some personal data on paper for the foreseeable future, for example, a list of registered attendees to take to the meetings. These must be kept in a locked file or drawer at home, not left out for others to see or take.

- If you need a lockable file, ask your staff contact to arrange for one to be supplied or for details of suitable types you can purchase yourself (claim the cost back via volunteer expenses or from the support group cash float).
- You must securely destroy all personal data kept on paper when asked to do so by Lymphoma Action (see **Q6** 'When should I delete or destroy personal data?' and **Q7** 'How should I delete or destroy personal data?' under *How do SGOs safely 'process' personal data?*).

Q4 How would I know that I'd been involved in a data breach?

A4 You might not know immediately, for example, if your computer or phone has been hacked or the system you are using is breached. If you've forgotten to Bcc attendees to emails, you might not realise until later or an attendee contacts you to complain or Lymphoma Action contacts you about a breach we've been told about.

If you aren't sure but only suspect there may have been a breach, report it.

Q5 What should I do if I think there has been a data breach?

A5 You *must* notify your staff contact or the Volunteering Development Manager **immediately**, whatever the day or time.

- Send an email or leave a phone message, which your staff contact will pick up as soon as they are available. If you think that the breach is a result of your computer or phone having been hacked, use a different device to contact Lymphoma Action. If you get an auto-reply or voicemail message that your staff contact is away, contact the Volunteering Development Manager.
- Include all the details you have about the breach or your suspicion of a breach in the message.
- Once you have done this, you have done everything that is required of you unless and until your staff contact or another member of Lymphoma Action staff asks you to take some additional action. In this case, please follow their instructions.
- **Do not** contact the person/people whose data has been breached or the person/people or organisation to which the data has been sent. There is a legal process which Lymphoma Action has to follow to inform those concerned.
- You may feel anxious about what has happened – **please try not to worry**. As an official volunteer you are an authorised person of Lymphoma Action, which means you are not personally liable if you have followed our policy and processes.

Q6 What happens after I report a suspected data breach?

A6 As soon as Lymphoma Action receives your message, you will be sent a holding response telling you of any action you need to take at this point and offering support. You might be asked for further details at this stage or later on. The focus is on finding out what went wrong and putting it right, rather than on blame.

There are some things Lymphoma Action is legally required to do under the GDPR, which it might help you to know, to understand what is happening and why, if you are ever involved.

The charity's Data Protection Officer (the CEO) and the Head of Business Development, will investigate and decide whether the breach is serious enough to be reported to the ICO (Information Commissioner's Office) and what actions to take. Some actions are legal requirements, so there is no discretion about them, including:

- Recording the breach in the GDPR Incident Log.
- Contacting everyone whose data has been breached to:
 - explain what has happened
 - offer apologies
 - outline actions taken, including to prevent this type of breach happening again
 - give contact details for named person at Lymphoma Action for additional information, to express concerns or make a complaint.

Others actions will be taken in relation to Lymphoma Action's own policies and processes, including: recording all communications with the SGO; understanding how this type of breach could be avoided in future; deciding on volunteer management responses and actions; changing training, induction, instructions and/or guidance to SGOs as a result of learning from the incident.

If you need support at any point during this process or afterwards, please get in touch with your staff contact or the Volunteering Development Manager.

Registering people at the support group

Q1 Where do I get the Support Group Registration Forms and Freepost envelopes?

A1 Ask your staff contact for more forms and Freepost envelopes. SGOs must not photocopy the forms as they change from time to time and contain legal notices relating to data protection, which have to be correct.

Q2 Who has to register at the support group?

A2 Everyone who attends must be given a Support Group Registration Form at their first meeting and asked to complete it, put it in the Freepost envelope and return it to one of the SGOs before leaving.

We need to know who is coming to the group for reasons of health and safety, insurance and quality control. We provide SGOs with the contact details of everyone who registers, so you can contact them with information about the meetings. Lymphoma Action staff also might need to contact attendees, for example, if the SGO(s) are unwell and a meeting has to be cancelled at short notice.

Q3 Does a partner/spouse/family member or friend who comes to the group with someone have to register too?

A3 Yes. Everyone who comes to the group must register. Even if all the contact details are the same, the carer must complete their own form. The health and safety and other reasons apply equally to them.

Carers also get - and are entitled to attend the group to get – support for themselves in understanding and supporting a loved one who has a lymphoma diagnosis, so they aren't just accompanying their partner, family member or friend. Some carers come to the group alone, when the person who has the diagnosis doesn't attend.

Q4 Does someone with another blood cancer (not lymphoma) attending the group have to complete a registration form?

A4 Yes. We still require a registration form if they wish to come to the group, for the health and safety and other reasons. So, the first part of the registration form, about coming to the group applies equally to them.

However, for the second part of the form, where we ask people to tick the box if they want to get information from Lymphoma Action, you should explain that the charity only provides information, events and support for people affected by lymphoma and not any other type of blood cancer. They may prefer to leave the boxes unticked as the information will not be relevant to them.

Q5 What if someone doesn't want to register?

A5 Since registration was introduced, we have had no reports of any attendee refusing to complete a form, so this is very unlikely.

If it does happen, the SGO should try to find out what the objection is and provide an answer that deals with it – see the next FAQ. However, registration is a condition of using this Lymphoma Action service, so if they continue to refuse, they can't remain at the support group.

Q6 What should I say to someone who doesn't want to register?

A6 It depends on what their objection is, but here are some possible objections and how to answer them:

a) "I don't want you sending me a load of information and fundraising asks."

Explain that the form has two parts. The first registers them for the group and is covered by a privacy notice under the personal details box that states we won't contact them about anything other than the support group. The second part of the form asks them if they want any other type of information from Lymphoma Action. To get it, they have to tick one of the boxes. If they don't want any other information, just leave these blank.

b) “I don’t want you giving my details to anyone else.”

Explain that details provided just for registering at the support group are never given to anyone else. If information is requested via the tick-boxes in the second part of the form, the ‘privacy notice’ just below the tick-boxes states that we will not sell or swap their details with any third party but may provide them to a sub-contractor that prints or delivers our information, for example, which is also bound by this notice.

c) “I don’t want to come to any further meetings.” How you deal with this depends on when they tell you.

- Usually, you’d ask for the completed form to be returned to you at the end of the meeting. If they tell you then, just say that you are sorry that they don’t want to come back but that a support group is not for everyone. Offer them an *Affected by lymphoma?* leaflet, which covers how to access our other services and information, which might suit them better. After the meeting, email your staff contact to let them know what happened, including the person’s name (from introductions or the register).
- If they tell you at the start of the meeting, when you give them the form, you will need to tell them that if they remain at this meeting they have to register and explain why - we need a record of them having been at the meeting in case of an accident, etc (see **Q2** in this section). Their choice is then to register or be asked to leave the meeting. Report what happened to your staff contact as soon as possible, including the person’s name (from introductions or register).

Q7 What happens to completed registration forms?

A7 In support groups led by volunteer SGOs, completed Support Group Registration Forms are put into the Freepost envelope provided and returned to the SGO at the end of the person’s first meeting, for posting. When it arrives at head office, the form is scanned and stored digitally. The paper form is retained for 6 months then securely destroyed.

In support groups led by a member of Lymphoma Action staff, they take the completed forms in their envelopes back to their office, where they scan them and enter them onto the Lymphoma Action system. The paper forms are retained for 6 months then destroyed securely.

Q8 What happens after someone registers for the support group?

A8 Their personal data from the form are recorded on the database along with any request for other information. Their name and contact details are then sent to the SGO(s) for that support group. The SGO(s) store them securely and use them only to contact the person about the support group or as instructed by Lymphoma Action.

The registration will continue for as long as the person continues to attend the support group (and see **Q10** in this section).

Q9 What should I do about registration for someone who comes back to the group after a break?

A9 It depends on whether they asked to be de-registered during the time they didn't attend or continued with their registration, even though they weren't going to meetings. If in doubt, ask them to complete another form.

- If they continued with their registration, you don't need to do anything. You will know this is the case because you will still be including them in your communications with registered attendees about the support group.
- If they de-registered, they will need to complete another Support Group Registration Form. You will know they had de-registered because your staff contact would have instructed you to securely delete or destroy their details from your records and not contact them again.

Q10 What if someone registered for the support group says they don't want to be contacted again about it?

A10 Clarify whether they mean that they don't want to come back to the support group again or if they just don't want you to contact them about meetings?

- If they don't want to come to the support group again, they can ask to be de-registered. They can do this by sending you an email including their full name, saying they want to de-register from the support group, which you will forward to your staff contact to action. If they don't have email, they can send a letter to Lymphoma Action head office or call the office main number 01296 619400.
 - SGOs should not do anything with the person's details on their own records until they get an email from their staff contact instructing them to do so.
- If they want to remain registered but just don't want to hear from you about support group meetings, tell them that you will pass their request to Lymphoma Action and someone will be in touch with them about this.
 - Report this to your staff contact, who will explain to them that the charity has to be able to contact them about meetings, for example, a cancellation or change of venue, and this is a condition of registration for the group.

How do SGOs safely 'process' personal data?

Q1 How do SGOs obtain contact details for people attending the group?

A1 When a Support Group Registration Form is received at Lymphoma Action, when it has been entered onto the system, the person's name and contact details are sent to the SGOs for that support group by their staff contact.

Q2 How should I store personal data?

A2 You can store personal data digitally or on paper, or both. Keep the number of records of personal data to an absolute minimum. For example, only store data on one computer or phone and only in one place on each.

Data stored digitally must be password protected. This means a password on the device and/or a password-protected account that cannot be accessed by anyone else.

The data should not be copied or backed up to external sources. If you accidentally delete someone's details, you can obtain them again by contacting your staff contact

Paper records must be stored in a locked cabinet, drawer or safe container. If you need to acquire a lockable file or box, ask your staff contact.

If you have a list of all attendees' details, remember that if you are asked to destroy one person's details, you will have to destroy the whole list. Consider whether it would be better to keep individual attendees' data separately.

Q3 How can I use support group attendees' personal data?

A3 SGOs must only use attendees' personal data to contact them about the support group or as directed by their staff contact or other member of Lymphoma Action staff.

Generally, only one email, letter or text (according to the details provided by the attendee) per meeting should be sent. This could include details of the next meeting, a summary of the speaker or activity at the last meeting, and any information your staff contact has asked you to include or said you may include.

Do not use the personal data to contact attendees for any other reason without specific instruction or permission from your staff contact or other member of Lymphoma Action staff.

Q4 Should I take a register of attendees at support group meetings?

A4 SGOs may take a register at meetings. It can be useful to keep track the number of attendees at the meeting and identify new people who need to complete a registration form. In the event of the meeting venue having to be evacuated in an emergency, a register can be used to account for everyone having safely left the building.

Ask your staff contact to provide you with the register or a pro-forma to populate and print. Only the person's name should be included, no other details and it is best to just ask them to put a tick against their name, rather than a signature.

After the meeting, once you have noted the number of attendees to do your report, you must either securely destroy the register or store it securely until you can give it to your staff contact.

Q5 What if the meeting venue wants a list of attendees?

A5 A venue is entitled to ask all users of their building to sign in on arrival for reasons such as health and safety, security or insurance. This should be done at the reception desk. However, venue staff may not have or see the SGO's list or register of attendees, as this would be a breach of data protection. If anyone asks for a list, explain these points and refer them to your staff contact who will deal with the matter.

Q6 When should I delete or destroy personal data?

A6 You should only delete or destroy personal data obtained from Lymphoma Action when instructed to do so by your staff contact or another member of Lymphoma Action staff.

When you receive this instruction, you must securely delete or destroy the information as soon as possible (See **Q7** 'How should I delete or destroy personal data?').

You may be asked to confirm that the personal data has been deleted or destroyed.

Q7 How should I delete or destroy personal data?

A7 This depends on how the data has been stored and used, whether digitally or on paper.

- **Digital** All the relevant personal data must be deleted from digital devices and systems, for example, in contacts lists as well as documents stored electronically, such as spreadsheets. Remember that you might have this data on more than one document and in more than one 'contacts' list on your phone, tablet, etc. They must also be deleted from your 'recycle bin' or 'deleted items'.
- **Paper** You will need to destroy all paper records that include the individual's name or contact details, which might involve having to create new lists. It isn't sufficient to just ink over the relevant personal data. Paper records must be destroyed by putting through a shredder or cutting up into pieces small enough that they could not be easily reconstituted to allow the personal data to be read. If you don't have the means to do this, please speak to your staff contact.

Social events outside support group meetings

Q1 What role do SGOs have in organising social events and can we use attendees' personal data?

A1 SGOs do not organise social events outside of support group meetings (see *Support Group Organisers' guide*). SGOs may not use attendees' personal data for any other purpose than contacting them about the support group.

However, attendees may wish to organise social events among themselves. You must not provide any personal data to anyone organising a social event or activity. Instead, the organiser must ask individuals if they are interested and, if so, whether they will provide their contact details.

You must be clear that this event or activity is not being organised or run by Lymphoma Action, that anyone wishing to take part is giving their data to the organiser on a personal and private basis.

Support group speaker contact details

Q1 How do I manage personal data for support group speakers?

A1 This depends on the capacity in which you are contacting them – professional or personal. Most speakers will be contacted in the professional capacity and it much simpler to do this because their contact details are usually treated differently under the GDPR.

- If you are contacting a speaker using their **personal (home) contact details**, these must have been obtained with their permission, then stored, used and deleted in exactly the same way as for support group attendees.
- If contacting a speaker using **professional (work) contact details**, it depends on whether or not their details are publically available, for example, on a website or social media platform, such as LinkedIn.
 - If publically available, they have waived the right to these being kept private. You can use and store these as you need (within reason).
 - If not publically available, you will only be given a person's contact details at work after contacting the organisation they work for via a general email or phone number. Treat these details as you would their personal (home) contact details under GDPR.

Q2 What if a speaker or organisation asks for personal details of support group members?

A2 You must never give the personal data of any attendee of the support group to a speaker or their organisation.

SGOs do *not* have permission to ask attendees if they may do this, either.

Attendees who wish to have contact can be given the contact details of the speaker or organisation, so they can get in touch themselves. You must be clear that they do so at their own risk and that Lymphoma Action does not endorse or encourage their doing so.