Storing and using personal data: Best practice summary for Cochrane Groups

As a Cochrane Group, the way you store and process personal data is governed by the EU General Data Protection Regulation (GDPR), which came into effect on 25 May 2018. GDPR applies to all organisations holding data on EU citizens.

GDPR requires strict data protection policies and practices within Cochrane. We could be liable for large fines if we do not comply with the legislation.

It is vitally important that all Cochrane Groups read this guidance and take necessary action.

What does GDPR mean for you?

- You will need to review and change how your Group stores and processes personal data
- You will need to review and change how your Group communicates with people

GDPR requires that personal data must be:

- Processed fairly and lawfully, in accordance with the rights of the data subject
- Processed for specific purposes in an appropriate way
- Adequate, relevant and not excessive in relation to the purpose
- Accurate and up to date
- Deleted when no longer necessary
- Kept secure using technological and organisational measures
- Not transferred outside the European Economic Area unless that country ensures adequate levels of protection for the rights of the data subject

Best practice guidelines:

- Everyone involved with Cochrane should have a Cochrane Account. By signing up for a Cochrane Account, people agree to us storing and processing their data. People can also view and edit their own personal details and communication preferences.
- Everyone with whom we communicate should have opted in to receiving communications.
- Personal data should not be kept without legitimate reason and unnecessary data should be deleted.
- Personal data should only be stored in Archie. Archie is regularly backed up and is secure (accessible only to those with permissions). Personal data (for example, names and email addresses) should not be stored locally in Group files or on spreadsheets.
- Archie workflows should be used fully at all stages of review production. When you store data in Archie, you do not need to worry about data protection compliance. Data in Archie are Cochrane’s responsibility.
- Personal data should not be shared via email, or with third parties.
Storing and using personal data: Guidance for Cochrane Groups

This guidance provides specific instructions to ensure compliance with our revised data policy: community.cochrane.org/organizational-info/resources/policies/data-policy

Our commitment

- We regularly review our policies to ensure that our central communications and IT infrastructure are GDPR compliant
- We have appropriate technological and organisational measures in place to protect the personal data of all staff, contributors, members and supporters – where these are stored in our central storage systems

Your responsibility

Key areas of Cochrane Group work involve the handling of personal data. You should review, and – if necessary – change your Group practices in relation to:

1. Recording personal details and creating new contacts in Archie
2. Newsletters and other communications that the law considers to be marketing
3. Storage of personal data outside Archie (e.g. external spreadsheets for mailing lists)
4. Editorial processes where you handle personal data (e.g. topic proposal forms, peer review)
5. Other Group activities where you handle personal data (e.g. providing training, hosting events)

Important definitions

Data are information stored electronically or in paper-based filing systems.

Data subjects include all living individuals about whom we hold personal data. A data subject need not be an EU national or resident. All data subjects have legal rights in relation to their personal information.

Personal data means data relating to a living individual who can be identified from that data (or from that data and other information in our possession). Personal data can be factual (name, address or date of birth) or it can be an opinion about that person, their actions and behaviour.

Anyone processing personal data must comply with the GDPR eight enforceable principles of good practice. These state that personal data must be:

1. Processed fairly and lawfully.
2. Processed for specific purposes in an appropriate way.
3. Adequate, relevant and not excessive in relation to the purpose.
4. Accurate and kept up to date.
5. Not be kept for longer than necessary.
6. Processed in accordance with the rights of the data subject.
7. Kept secure using technological and organisational measures.
8. Not be transferred outside the European Economic Area unless that country ensures adequate levels of protection for the rights of the data subject.
If you have any questions about this or need further assistance, please contact the Community Support team: support@cochrane.org

1 Recording personal details and creating new contacts in Archie

People should know we are storing their personal data. People are entitled to see and edit the data we hold about them

- Encourage new Group contacts to create their own Cochrane Accounts.
- Use Archie to store all personal contact data. Archie is secure.

**Encourage contacts to create their own Cochrane Account**

When people contact your Group wanting to get involved with Cochrane’s work, ask them to sign up for a Cochrane Account: account.cochrane.org. This avoids collecting personal data on Group contact forms. By activating their Cochrane Account, contacts consent to Cochrane storing and using their data.

Any existing contacts in Archie who have not activated their Cochrane Account, can do so by clicking on the ‘Reset password’ link on any Cochrane Account login page, e.g. account.cochrane.org

Do not add contact details to local lists or databases. When people sign up centrally they have access to their My Account profile and can control their personal details and communication preferences.

Currently My Account allows users to update name, country and email. However, you can add relevant Group roles and affiliations to the person’s Membership Project account in Archie as required. Future My Account developments will allow users to complete their full profile.

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**TOP TIP**

If you want your Group to become a contact’s primary entity, use the ‘Suggest Changes’ function in Archie to request this. The Community Support team manage all Membership Project user accounts and can reassign them to your Group.

**Creating new contact records in Archie**

When you create a new contact record using the Archie New Person Wizard, you will also create a linked Cochrane Account. Newly-created contacts receive an email informing them that we are storing their data and inviting them to activate their account. Account activation is desirable (as contacts then agree to the terms and conditions for Cochrane storing and processing their data) but not compulsory.

If the contact provided their personal details on a Group Contact or Registration form, delete the form once the person’s details are stored in Archie.

You should not need to collect data on individuals outside of our core systems. If you do this, you should inform the individual about how you will store and process their data and seek their consent for doing so. You must have a lawful basis for storing personal data.¹

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¹ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/
The Archie Help file provides guidance on dealing with deceased contacts, contacts with no valid email address and contacts who request that their personal information be deleted from our systems.

2 Newsletters and other communications

Opting in to communications: workflow emails and newsletters

Everyone who has accepted a role in the review production process (e.g. author, peer reviewer) is automatically opted in to Archie workflow emails. However, you need to ask people involved in your Group to subscribe to other types of communication, such as newsletters or mailing lists.

GDPR classes newsletters and mass mailings as marketing communications. GDPR requires that people actively opt in to marketing communications. Assume everyone is opted out unless they have actively subscribed. The fact that people have received a newsletter in the past does not count as an opt in. If you are in any doubt you should remove people from the mailing list and write to them to ask them to re-subscribe.

There are significant practical barriers to managing all Cochrane Group newsletters centrally. Groups can continue to manage their own mailing lists, provided you adhere to the standards below.

Recommended processes for Group newsletters and mailing lists

1. Use dedicated software such as MailChimp for your newsletter. We can provide templates and help with branding. MailChimp is free to use up to 2000 subscribers².

2. You should not keep a spreadsheet of mailing list subscribers locally. Store the personal data of your subscribers as an imported list in MailChimp.

3. Take appropriate technical and organisational measures to prevent unauthorised access to the data; protect your Group’s MailChimp account with a suitably strong password.

4. You must not create a mailing list from Archie contact details – people must subscribe to your mailing list. You can write to people to inform them about your mailing list, but you must not add people to mailing lists by default. Performing a bulk export of contact information from Archie to send any mailings is not permitted according to the law.

5. Sign-ups to the mailing list must be explicit, clear, and recorded. You can send potential subscribers a link to sign up to the mailing list and incorporate a message about your newsletter into standard communications to people joining your Group.

6. If you already use MailChimp and you have existing newsletter subscribers who have explicitly signed up then no action is required for those contacts, you can keep contacting them as before.

7. People must be able to unsubscribe by clicking a button or hyperlink in the email. The following disclaimer must be included next to, or directly below the unsubscribe button / link. "Please note: unsubscribing will remove you from the Cochrane XXXXX Group’s mailing list, but it will not automatically unsubscribe you from other Cochrane Groups’ mailing lists or from Cochrane’s organizational mailing lists which you can manage at account.cochrane.org."

² MailChimp offer guidance here: mailchimp.com/resources/guides/getting-started-with-mailchimp/
8. Your newsletter should include relevant content such as information about Group activities, upcoming events, news, recent publications, and updates related to the Group's area of interest.

9. Do not use or share the recipients' details for any purpose other than to send the newsletters.

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**TOP TIP**

Advertise your newsletters sign-up link on your website. See for example: oralhealth.cochrane.org/news-events

You can also promote your newsletter through social media channels.

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**Other communications**

The restrictions that apply to marketing communications, do not apply to essential communications with specific individuals to allow them to complete their work with the Group.

By accepting a Group role such as an author or peer reviewer, people are consenting to receive communications related to their work in this role. This includes:

- Workflow emails
- Personal emails to named individuals about a specific task
- Messages to groups of individuals, such as editors or authors, about something specific to their role, e.g. if you want to make all of your editors aware of a new checklist, you can send a group email. Or, you set a new policy to accept review submissions that use ROB 2, and write to all authors who are actively working on reviews to convey this message.

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**3 Storage of personal data outside Archie**

**Why use Archie to store your data?**

Cochrane provides central systems to store personal data and you should use these systems. This ensures that all data are centrally, securely managed and kept up to date. **You should use Archie to store all data on people. You should avoid storing data on spreadsheets or other local files.**

To comply with GDPR legislation, you need to:

- keep data secure,
- keep data up to date,
- ensure data held are correct; and
- ensure data held are relevant.

Archie can do this for you. If you use Archie to store personal data, you do not need to worry about your Group’s compliance with GDPR. You also help to ensure all our systems contain up to date information.

If you store personal data on spreadsheets, the burden of updating is greater, and the risk of the information being out of date, inaccurate and insecure is higher. Externally-stored data will also become out of date if a user changes their own contact details in My Account.
GDPR requires that data be kept up to date. With a single database we can control what personal data are stored and be GDPR compliant. Importantly, if a person requests disclosure or deletion of their personal data, this can also be shared or erased from one source. If they are listed in external spreadsheets these also need to be searched and that data erased. The burden of doing this is the primary argument for avoiding spreadsheets.

Storing data safely outside Archie

If you need to keep data on external files or spreadsheets, you should only include minimal personal information. Please avoid storing several types of personally identifying information together, such as lists of names and email addresses. If they are necessary, spreadsheets and local files must be securely stored, with password protection, encryption and written procedures on how they are kept up to date, relevant and correct. Do not print spreadsheets or other files out or send them via email.

Please take this opportunity to review the data you hold locally in spreadsheets or other files outside of Archie:

- Is it essential to the effective functioning of your Group to store these personal data? If not, please delete/securely destroy them.
- If storing these personal data is necessary, could the data be stored on Archie instead? If so, please add all relevant details to Archie and delete/destroy other files.
- If the data can’t be stored in Archie, please only store the minimum of data necessary. Document how you will keep records up to date and ensure their security.

4 Editorial processes

At specific points in the editorial process, editorial base staff need to handle personal data. Best practice guidelines on how to do this are detailed in the table below.

<table>
<thead>
<tr>
<th>Process</th>
<th>Specific action</th>
<th>Why might this be a data protection issue?</th>
<th>What can your Group do to protect personal data?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting involved request</td>
<td>Adding new Group contacts and authors</td>
<td>Do not add people to mailing lists / databases without allowing them to confirm communication preferences</td>
<td>Encourage people interested in your Group to create their own Cochrane Account. This avoids the need for collecting personal data on Group contact forms. New authors and peer reviewers can add / edit their own affiliations and other details as necessary, once they have a role granting access to Archie. If you create new Group contacts, ensure you delete any Group Contact or Registration form once the personal data are stored in Archie. In the future, non-activated accounts may be regularly deleted where the contact has no document role.</td>
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| Title proposal     | Circulating title proposals for comment                                          | Sharing people’s contact details by email is not secure                                                   | When circulating a title proposal to editors, you do not need to include authors’ full addresses, emails, phone numbers, etc. We suggest you either:  
  • Remove contact information from the form before circulating  
  • Edit your Group’s title proposal form to ask for name, job title and institution only  
  Remember to store any documents containing contact details on Archie, not in local folders. |
5 Other Group activities: training and events

Many Cochrane Groups, Centres and Fields provide training courses and host events such as symposia, workshops and seminars. Individuals signing up for training courses and events should be encouraged to set up a Cochrane Account so that their data are stored in Archie. Sign-up forms and lists of attendees should be stored securely and should be deleted once participants’ data are in Archie.

We aim to make functionality available on Group websites to allow you to manage training and events online. People will log in with a Cochrane Account and make an online booking. This will mean all training data are stored centrally. Ultimately, a contact’s Cochrane Account will keep a record of all Cochrane training courses and events attended, and the individual will be responsible for checking that their contact details are up to date.

If you are using a third-party events management system, please check their privacy policy to ensure it is GDPR compliant. Encourage all participants to create a Cochrane Account and share the training data with the Community Support team after the event to maintain a complete training record in each individual’s Cochrane Account profile.

6 Best practice overview

- Everyone involved with Cochrane should have a Cochrane Account. By signing up for a Cochrane Account, people agree to us storing and processing their data. People can also view and edit their own personal details and communication preferences.

- Everyone with whom we communicate should have opted in to receiving communications (everyone with a Group role and a Cochrane Account is automatically opted in to workflow emails).

- Personal data should not be kept without legitimate reason and unnecessary data should be deleted. Think before adding data to systems and ask yourself why we need that personal data. If you come across any personal data that is no longer necessary, delete it.
• Personal data should only be stored in Archie. Archie is regularly backed up and is secure (accessible only to those with permissions).

• Personal data (for example, names and email addresses) should not be stored locally in Group files or on spreadsheets. Only use spreadsheets where absolutely necessary and where you have processes documented for how you will keep personal data in them up to date and set retention policies for when you no longer need the data. Most spreadsheets serve a temporary process and can be deleted, consider setting calendar reminders to delete temporary spreadsheets created.

• Archie workflows should be used fully at all stages of review production. When you store data in Archie, you do not need to worry about data protection compliance. Data in Archie are Cochrane’s responsibility.

• Avoid circulating personal data via email as breaches of security can easily occur. If you have to share data, think before you share: does the recipient need all the data? Can personal data be removed?

• Personal data should not be shared with third parties outside Cochrane.

If you have questions or concerns about any of the above please contact the Community Support team: support@cochrane.org