

## GACD Research Network

### Data and communications privacy notice

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To be reviewed: August 2024

The Global Alliance for Chronic Diseases (GACD) is registered as a Charitable Incorporated Organisation (CIO) with the Charity Commission for England and Wales under the charity number 11138223-22 and the name GACD Action; it is a linked charity to the Medical Research Foundation. This privacy notice will explain how GACD uses the personal data submitted by you.

GACD requires information on project staff to facilitate the activities of the Research Network as a whole. Collaboration and networking amongst the worldwide research teams is a crucial aspect of GACD and is expected to increase the impact of the research that is conducted and result in knowledge sharing and capacity strengthening. Please see our [website](#) for the GACD Research Network terms of reference.

This privacy notice is based on the GACD Data Protection Policy, outlined in [Annex 1](#).

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#### 1. What data do we collect?

GACD will request from you the following data:

*Essential for Research Network operations*

- Name
- Email address
- Organisation or institution
- Country of organisation or institution
- GACD project details
- Role on GACD project (for example principal investigator)
- Attendance of GACD events, including the Annual Scientific Meeting

*Optional data*

- Secondary email address
- Personal assistant's email address
- Gender identity and nationality (for diversity monitoring purposes only)

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#### 2. How do we collect your data?

You directly provide GACD with most of the data we hold. We collect and process data when you:

- Sign up to participate in the GACD Research Network.
- Attend a GACD event, such as the Annual Scientific Meeting.
- Email us directly to provide information.

As part of the project annual updates, GACD will request updates to existing data from project principal investigators. Project staff may request to update their data at any time by emailing [admin@gacd.org](mailto:admin@gacd.org) or a GACD staff member; once updated, the GACD staff member will confirm this via return email.

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### 3. How will we use your data?

GACD has requested data on you so that we can:

- **Communicate with the whole Research Network while maintaining data privacy.**

For example:

- Invitations to the Annual Scientific Meeting, updates on Research Programmes and working groups, and opportunities for collaboration. Scheduled communications to the whole Research Network will usually be limited to monthly.
- Research Programme co-chairs may wish to communicate via email with the researchers on their respective Research Programmes. Such communications are at the discretion of the co-chairs. Content will be directly related to the remit of GACD and work of the Research Programme.
- The whole Research Network may be contacted *ad hoc* when specific opportunities or necessary activities arise; for example, surveying the Research Network regarding the impacts on their projects of the global COVID-19 pandemic. Such communications will always relate to the remit of GACD and the work of the Research Network.

- **Facilitate collaboration.**

For example, connecting you to a researcher on a different project within the GACD Research Network as you have both expressed interest in forming a new working group but have not previously met. Your contact details will only be shared within the GACD Research Network community and only the minimal necessary information. Consenting to this use of your data is optional, but highly recommended.

- **Generate analytics.**

For example, how many projects does GACD currently fund in the WHO AFRO region, or is any gender underrepresented in working groups. Such analytics may be used to inform future Research Network activities or be cited in GACD reports. Results of such analytics will not be traceable to individuals.

GACD uses third party platforms to assist with data storage, processing, and monthly newsletters: Airtable (for the Research Network database) and SendGrid (to maintain privacy with all communications). You will not be contacted directly by any of the third party platforms. All platforms have robust data protection policies.

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### 4. How do we store your data?

GACD securely stores your data in a specially designed, dedicated database using the platform Airtable. The database is appropriately secured with access restricted to GACD staff only. For more information on Airtable's data security policy, please visit their [website](#).

Data stored and processed by GACD will not be shared with other individuals or organisations external to the GACD Research Network. If GACD believes you would benefit from connecting with an external person or organisation, we will contact you to gain explicit permission before taking any action.

GACD will keep your data for the duration of your GACD project. Once this time period has expired, you will remain a member of the Research Network as a legacy member. See the Research Network terms of reference [here](#).

If you choose to be removed from the database at your project's completion or for another reason, GACD will remove all identifying information (name, email address) and keep non-specific data. This will allow us to run retrospective, aggregated analytics.

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## 5. What are your data protection rights?

GACD would like to make sure you are fully aware of all your data protection rights. Every user is entitled to the following:

- **The right to access** – You have the right to request GACD for copies of your personal data.
- **The right to rectification** – You have the right to request that GACD correct any information you believe is inaccurate. You also have the right to request GACD to complete the information you believe is incomplete.
- **The right to erasure** – You have the right to request that GACD erase your personal data, under certain conditions.
- **The right to restrict processing** – You have the right to request that GACD restrict the processing of your personal data, under certain conditions.
- **The right to object to processing** – You have the right to object to GACD's processing of your personal data, under certain conditions.
- **The right to data portability** – You have the right to request that GACD transfer the data that we have collected to another organisation, or directly to you, under certain conditions.

If you make a request, we have one month to respond to you. If you would like to exercise any of these rights, please contact us.

**Email us at:** [admin@gacd.org](mailto:admin@gacd.org)

**Or write to us at:** Global Alliance for Chronic Diseases, Wellcome Trust, 215 Euston Road, London NW1 2BE, United Kingdom

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## 6. Changes to our privacy notice

GACD keeps this privacy notice under regular review and places any updates on the website.

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## 7. How to contact us

If you have any questions about GACD's privacy notice, the data we hold on you, or you would like to exercise one of your data protection rights, please do not hesitate to contact us.

**Email us at:** [admin@gacd.org](mailto:admin@gacd.org)

**Or write to us at:** Global Alliance for Chronic Diseases, Wellcome Trust, 215 Euston Road, London NW1 2BE, United Kingdom

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## 8. How to contact the appropriate authorities

Should you wish to report a complaint or if you feel that GACD has not addressed your concern in a satisfactory manner, you may contact the Information Commissioner's Office [here](#).

## Annex 1 – GACD Data Protection Policy: Key points

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### **1. *Processed lawfully, fairly and in a transparent manner (lawfulness, fairness, and transparency).***

- Having a legitimate ground for collecting and using personal data.
- Not using personal data in a way that would have an adverse effect.
- Being transparent about how you intend to use personal data and provide privacy notices where appropriate.
- Handling personal data in a way that the individual would reasonably expect.
- Ensuring that you do nothing unlawful with personal data.

### **2. *Collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes (purpose limitation).***

- Being clear about why you are collecting personal data and what you will do with it.
- Providing privacy notices when collecting personal data.
- Ensuring that any additional processing of personal data is fair.

### **3. *Adequate, relevant, and limited to what is necessary in relation to the purposes for which they are processed (data minimisation).***

- Only processing the personal data that is necessary.

### **4. *Accurate and, where necessary, kept up to date (accurate).***

- Taking reasonable steps to ensure the accuracy of any personal data held.
- Ensuring that the source of the personal data is clear.
- Carefully considering any challenges to the accuracy of personal data.
- Considering whether it is necessary to update the information.

### **5. *Not kept for longer than is necessary for the purpose (storage limitation).***

- Reviewing the length of time you keep personal data for.
- Considering the purpose you hold the personal data for in deciding whether, and how long, you retain it.

### **6. *Processed in a manner that ensures the security of data using appropriate technical and organisational measures against unauthorised or unlawful processing, loss, damage, or destruction (integrity and confidentiality).***

- Designing and organising security measures are in place, backed by robust policies and procedures and reliable, well-trained employees.
- Reporting security breaches promptly so that they can be reported to the Information Commissioner's Office within the required 72 hours' timescale.