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# PRIVACY POLICY

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This Privacy Policy was last updated on 14<sup>th</sup> September 2020. For the changes made since the last version of this policy please see section 14.

### 1. Introduction

ERNDIM is committed to respecting our customers' privacy and protecting their personal information from misuse or authorised disclosure and complying with privacy laws. ERNDIM values its reputation and aims to maintain high ethical standards in the conduct of our business affairs.

This privacy policy applies across all websites that we own and operate and all services we provide including how we use any personal information that we collect.

Please read this Privacy Policy carefully and ensure that you understand it. Your acceptance of our Privacy Policy is deemed to occur upon when you first start using our services.

If you have any questions, comments or concerns about an aspect of this privacy policy or how ERNDIM handles your information please email [admin@erndim.org](mailto:admin@erndim.org).

### 2. Who are we

In this document "**We/Us/Our**" means ERNDIM (European Research Network for evaluation and improvement of screening, Diagnosis and treatment of Inherited disorders of Metabolism).

ERNDIM is a charitable foundation, registered with the Maastricht Chamber of Commerce (Kamer van Koophandel, [www.kvk.nl/english](http://www.kvk.nl/english), registration number 41078752); registered address: The Accounting House, Sheepbridge Centre, Sheepbridge Lane, Chesterfield, Derbyshire, S41 9RX.

ERNDIM is the controller and is responsible for your personal data. We have appointed a Data Protection Officer who is responsible for the content in this Privacy Policy.

Data Protection Office, ERNDIM Administration Office  
 Genetic Medicine, 6<sup>th</sup> floor, St Mary's Hospital  
 Oxford Road, Manchester, M13 9WL, United Kingdom.  
 Telephone: +44 (0) 161 276 6741  
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 Email: [admin@erndim.org](mailto:admin@erndim.org)

### 3. What information do we collect

In this document "**Personal data**" means any and all data that relates to an identifiable person who can be directly or indirectly identified from that data. In this case, it means personal data that you give us directly or

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that is provided to us by another named contact for an EQA scheme participant. This definition shall, where applicable, incorporate the definitions provided in the UK's Data Protection Act 2018 which is the UK's implementation of the EU Regulation 2016/679 – the General Data Protection Regulation (“GDPR”).

The Personal data we collect from you includes:

- Names, titles, and email addresses of named contacts for EQA scheme participants, supplied during the EQA registration process or during the EQA scheme year.
  - If you are the primary contact for a laboratory, you will need to check with the people whose details you register as the other contacts for your laboratory to make sure that that they are happy for you to share their personal information with us and for us to use it in accordance with this privacy policy.
- Names, titles, and email addresses of people who ask us to contact them for defined purposes, not related to EQA scheme participation.
- Questions, queries, or feedback from you, including your email address if you contact ERNDIM.
- Financial information of people who submit claims for travel or other expenses due to attendance at ERNDIM meetings or successful Grant applications.

We also collect financial information for your Institute during the EQA scheme registration process.

The legal basis for processing the data we collect is to allow us to provide the service(s) you have agreed to (i.e. EQA scheme participation) or given specific consent for.

It is important that the data we hold about you is accurate, please contact us ([admin@erndim.org](mailto:admin@erndim.org)) regarding any changes and updates.

#### 4. Why we need it

We use the data you provide for the purposes of :

- Providing a service in the form of the ERNDIM EQA schemes and support activities related to EQA scheme participation. These include:
  - Administration and financial process related to EQA scheme participation and support activities.
  - Carrying out feedback and other surveys related to EQA scheme participation and support activities.
  - Organising meetings related to EQA scheme participation.
  - Providing you with information related to the EQA schemes and support activities.
- Payment of travel expenses for committee members or recipients of travel grant awards.
- If you provide specific consent, we will also use the data you provide to send you information related to:
  - ERNDIM meetings or ERNDIM events at meetings which are not directly related to EQA scheme participation.
  - Meetings or other activities from third parties approved by ERNDIM.

#### 5. What do we do with your data

We treat all personal data as confidential. The identity of EQA participants is confidential and known only to those persons involved in the operation of the EQA scheme, unless the named contacts for a participating laboratory waives confidentiality for the purpose of discussion and mutual assistance (for example to improve performance).

ERNDIM sub-contracts some EQA and financial activities to supplier organisations. The data we collect may be shared with these sub-contractors for the purposes of EQA participation. All our sub-contractors are required to have a confidentiality agreement within their contract with ERNDIM.

We will not:

- sell or rent your data to third parties
- share your data with third parties for marketing purposes

We will share your data if we are required to do so by law (for example by court order, or to prevent fraud or other crime) or if we are contacted by a regulatory body. If a regulatory body requires the EQA results to be provided directly by ERNDIM we will contact the relevant participants before sharing any information.

#### 6. Where your data is processed and stored

We process data within the UK, the EU, the EEA, and countries deemed by the UK as having adequate safeguards for protecting personal data. These countries are recognised by the UK as having suitable

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safeguards for the rights and freedoms of individuals and recourse processes by which data subjects can exercise their rights.

We will only consider transferring your data to a third country which is not recognised by the UK as having suitable safeguards etc. if the either a contractual agreement or data transfer agreement is in place.

## 7. How long we keep your data for

We will hold your personal data related to EQA scheme participation for as long as you remain a named contact for a laboratory participating in the ERNDIM EQA schemes.

If you stop being a named contact for an existing EQA participant, we will hold your details for a maximum of 5 years after you stop being a named contact.

If your laboratory stops participating in the ERNDIM EQA schemes while you are a named contact for the laboratory, we will hold your personal information for a maximum of 5 years after the last participating scheme year. After 5 years we will remove personal names and email addresses from the information for previous EQA participants. However, we will store the participation and performance data related to previous EQA participants for 10 years after the last participating scheme year.

If you send us a claim for travel expenses or a travel grant, we will hold the full details until the end of the next financial year. After this time we will remove any personal financial information from the documents we hold but we will retain your name and email address for a further 5 years.

If you have consented to us contacting you for purposes other than those related to EQA scheme participation or payment of travel expenses or grant awards, we will keep your data until you tell us that you wish to be removed from the relevant contact list or for a maximum of 5 years after you last gave your consent to be contacted.

If we are storing your information for purposes other than those related to EQA scheme participation or payment of travel expenses or grant awards and you wish to have your personal information removed from our records please contact us at [admin@erndim.org](mailto:admin@erndim.org).

## 8. Children's privacy protection

Our services are not designed for, or intentionally targeted at, children 13 years of age or younger. We do not intentionally collect or maintain data about anyone under the age of 13.

## 9. How we protect your data and keep it secure

We are committed to doing all that we can to keep your data secure. We have set up systems and processes to prevent unauthorised access or disclosure of your data.

We also make sure that any third parties that we deal with keep all personal data they process on our behalf secure.

## 10. Your rights

You have the right to request:

- information about how your personal data is processed.
- a copy of that personal data.
- that anything inaccurate in your personal data is corrected immediately.

You can also:

- raise an objection about how your personal data is processed.
- request that your personal data is erased if there is no longer a justification for it.
- ask that the processing of your personal data is restricted in certain circumstances.

If you have any of these requests, get in contact with our Data Protection Officer.

## 11. Contact us or make a complaint

Contact the ERNDIM Data Protection Officer (DPO) if you:

- have any questions about anything in this document
- think that your personal data has been misused or mishandled

Data Protection Officer, ERNDIM Administration Office

Genetic Medicine, 6<sup>th</sup> floor, St Mary's Hospital

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You can also make a complaint to the Information Commissioner, who is an independent regulator. You can find the contact details of the UK ICO here: <https://ico.org.uk/global/contact-us/>

## 12. Use of cookies and other technologies

A "cookie" is a small data text file that is placed in your browser and allows ERNDIM to recognize you each time you visit this site (customisation etc). Cookies themselves do not contain any personal information, and ERNDIM does not use cookies to collect personal information. Cookies may also be used by 3rd party content providers such as newsfeeds.

## 13. Links to other websites

This website contains links to other websites. This privacy policy only applies to [www.erndim.org](http://www.erndim.org).

If you follow a link to another website from this one, read the privacy policy on that website to find out what it does with your information.

## 14. Changes to this policy

We will review and update this privacy policy at least once a year. When this happens the 'last updated' date at the top of this page will also change. Any changes to this privacy policy will apply to you and your data immediately.

If these changes affect how your personal data is processed, ERNDIM will take reasonable steps to let you know.

This policy was last updated on the 14<sup>th</sup> September 2020.

Changes made to this policy are:

| Version | Date              | Change   |
|---------|-------------------|--|
| -       | 30 August 2018    | Privacy Policy published to comply with the requirements of new European data protection laws (specifically, the General Data Protection Regulation).  |
| 1       | 13 September 2019 | Document Control header and footer added; table of contents added.   |
| 2       | 14 September 2020 | Section 3 updated to include a reference to the UK's Data Protection Act 2018 which is the UK's implementation of the EU Regulation 2016/679 – the General Data Protection Regulation ("GDPR")<br>Section 6 updated to recognise that data is processed in the UK which is no longer part of the EU. |

**END**