



MPS Society



Phone: +44 (0) 345 389 9901
Email: mps@mpssociety.org.uk
www.mpssociety.org.uk

Phone: +44 (0) 345 260 1087
Email: info@rd-rp.com
www.rd-rp.com

MPS House, Repton Place, White Lion Road, Amersham, Buckinghamshire. HP7 9LP. UK.

Policy No. 1P

DATA PROTECTION COMPLAINTS POLICY

The Data Protection Act 2018 is the main law governing data protection. You have the right to complain directly to us if you consider that we have breached data protection laws because of the way we have handled your personal data (or the personal data of someone you are acting on behalf of). This Policy explains your right to complain and how we will handle your complaint.

1. Roles and responsibilities

- a) Our Data Protection Officer (DPO) is responsible for handling data protection complaints within our organisation. They will work alongside other members of our organisation who have been identified as relevant to the investigation of each complaint.
- b) All staff are responsible for recognising data protection complaints.
- c) Staff who receive or identify a data protection complaint, whether in person, via social media or through any other channels, must inform the DPO and Executive Assistant as soon as possible.
- d) We are committed to handling data protection complaints in line with our legal obligations and in an accessible, fair, transparent and timely manner. We will handle complaints confidentially and only share information where appropriate to investigate and resolve the complaint, as required or authorised by law or otherwise in accordance with our privacy notices.

2. Types of complaint

- a) Examples of a data protection complaint include (but are not limited to) the following:
 - the way we have responded to a subject access request (SAR), or other data rights request (see our separate 'policy on your rights in relation to your data' for information on individual data rights)
 - the security measures we have used to store your information (e.g. where you have been impacted by a data breach); or
 - how we have collected or used your personal information (e.g. where we have stored it, how long we have kept it for, or its accuracy).

This list is not exhaustive. You have the right to complain to us at any time if you consider that there has been an infringement of any of your rights in relation to your personal data. Information on how we handle your personal data is set out in our separate privacy notices.

- b) Complaints about other matters that do not relate to data protection, such as customer service issues, will not be treated as a data protection complaint. If you have a complaint that is not about data protection, please refer to our Feedback and Complaints Policy which can be found on our website.
- c) If we are not sure whether you are making a data protection complaint, we will contact you to clarify the nature of your complaint.
- d) Employees who want to raise a grievance should do so under our grievance procedure.
- e) If your complaint relates to whistleblowing, please read our separate whistleblowing procedure.

3. How to make a data protection complaint to us

- a) You can submit a complaint directly to us using any of the following methods:

MPS Society

- Using our online form
- Email the Data Protection Officer at dataprotection@mpssociety.org.uk
- Post to the Data Protection Officer, The MPS Society, MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP.
- Phone 0345 389 9901

RDRP

- Using our online form
- Email the Data Protection Officer at dataprotection@rd-rp.com
- Post to the Data Protection Officer, Rare Disease Research Partners, MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP.
- Phone 0345 260 1087

This is not an exhaustive list. We will take appropriate steps to respond to data protection complaints that we receive from any other channels, including via social media.

- b) We will comply with our duty to make reasonable adjustments to our data protection complaints process for disabled people under the Equality Act 2010. If you feel that you would benefit from any adjustments to our data protection complaints process, you should raise this with us when making your complaint.

In the event that a complaint is not dealt with satisfactorily, the matter can be raised with the ICO, Wycliffe House, Walter Lane, Wilmslow, Cheshire SK9 5AF.

Helpline number: 0303 123 1113
ICO website: <https://www.ico.org.uk>

4. Complaints made on social media

- a) Although data protection complaints may be made on social media, we would advise that a complaint may be dealt with more efficiently and effectively if it is made using one of the methods set out above.
- b) Where we identify a data protection complaint about our organisation on social media, we will take appropriate steps to respond to the complaint in line with this Policy. However, as responding on social media is not usually a secure way of providing information, we will ask the individual making the complaint for an alternative contact method that we can use to respond to their complaint.

5. Complaints from children

We are committed to protecting the privacy of children who interact with our services in accordance with UK GDPR. This applies to all children under the age of 18 years.

We will evaluate a child's capacity to exercise their data rights based on competence rather than a fixed age limit (children aged 12 yrs and over are assumed to have sufficient competence). Where a child lacks capacity to understand their rights a parent or legal guardian can act on their behalf. We will always encourage/prompt a child to consult a trusted adult before finalising any complaint.

6. Responding to your complaint

- a) When we receive a data protection complaint, we will acknowledge receipt within 10 days of receiving it.
- b) If we have any doubts about your identity, we may need to ask you for proof of ID before we respond to your complaint.
- c) Complaints made on your behalf by a third party must be accompanied by evidence that the third party is authorised to act on your behalf. If this is not provided, we will contact the third party to ask that such evidence is provided before we respond to your complaint. If we are unsure whether a letter of authority is valid, we will contact you about this before we respond to your complaint.
- d) We will take appropriate steps to respond to your complaint without undue delay, including making enquiries into the complaint and keeping you informed about the progress of our investigation and timescales for the next update or outcome.
- e) We may need to contact you to request further information to assist with our investigation. It may take us longer to investigate and resolve complaints which are complex, serious or which relate to multiple data protection issues.
- f) Following our investigation, we will inform you of the outcome of your complaint without undue delay, explaining our findings, whether the complaint is upheld (in whole or in part), any action taken or proposed, and, where no action is taken, the reasons for that decision.

7. Complaints about data processors

Where we receive a complaint that relates to the processing of personal information by our service providers, we will ask them to provide us with information relevant to the complaint without undue delay and in line with our contractual terms with the service provider.

8. Training

We will provide training for all staff on recognising a data protection complaint and what to do if they receive one, including where to direct a complaint within our organisation.

9. Record keeping

- a) We will keep a record of:
 - the date we receive the data protection complaint
 - our acknowledgement
 - any relevant conversations and documents
 - the outcome of the complaint; and

- any actions we take because of our investigation.
- b) We will use these records to demonstrate compliance, for audit and monitoring purposes, training, to support consistent handling and to identify recurring issues, trends or areas for organisational improvements or remediation.
- c) We will not retain personal data relating to complaints for longer than is necessary. More information on our retention periods is set out in our Data Retention Policy available on request.

10. Document owner

The Data Protection Officer is the owner of this policy document and must ensure that it is periodically reviewed according to the review requirements herein.

The latest version of this policy document dated 21.10.2026 is available to all employees of the MPS Society/RDRP on the Company server.

This policy document was approved under the MPS Society's policy approval process on a version-controlled basis.

Name of GCEO: Bob Stevens

Date: 21.10.2026

Document History					
<i>Version</i>	<i>Author / Reviewer</i>	<i>Role</i>	<i>Date</i>	<i>Changes</i>	<i>Next review due</i>
1.0	Peninsula	Employer Support	30.09.2026	First version	

The Society for Mucopolysaccharide Diseases (the MPS Society) is a Registered Charity No: 1143472.

Registered as a Charity in Scotland No: SC041012.

Registered as a Company limited by guarantee in England & Wales No: 7726882.

MPS Commercial is a Private Limited Company Registered No 08621283. MPS Commercial trades as Rare Disease Research Partners and is a wholly owned, not for profit subsidiary of the Society for Mucopolysaccharide Diseases (the MPS Society). Registration details as above. Rare Disease Research Partners social objectives are to reinvest any surplus to support the mission of the MPS Society to transform the lives of patients through specialist knowledge, support, advocacy and research.