



Society for Mucopolysaccharide Diseases

Policy No. 1C DATA RETENTION and DISPOSAL POLICY

The Society for Mucopolysaccharide Diseases retains personal data in accordance with statutory requirements or for a longer period of time should we need to under legitimate interests (exemptions). The periods relating to different personal data categories are appropriate and not longer than necessary in this respect.

Record of Statutory Requirements Data Retention Periods Relevant to the Business of the MPS Society and its wholly own subsidiary Rare Disease Research Partners

Medical

Accident books, accident records/reports: 3 years after the date of the last entry.

Accounting

Accounting records: 3 years for private companies, 6 years for public limited companies.

Credit card account numbers must be destroyed in a manner that will render them unreadable after their useful life of 7 years has expired.

Members

All members' personal data that is relevant under legitimate interests will be retained for 6 years upon which this will be reviewed.

Advocacy

As part of the Society for Mucopolysaccharide Diseases commitment to our patient community we recognise there are circumstances when it may not be possible to gain consent e.g. when safeguarding principles apply or when there is an emergency intervention. In this case records will be retained for a period of one month and where retained will be anonymised. In all other cases consent must be obtained before services can be provided. Records will be retained for 6 years then will be reviewed and if appropriate the relevant data will be anonymised. Identifiable data will then be deleted securely.

Children

Records relating to children until the child reaches the age of 25. At this point the records will be reviewed and securely destroyed if appropriate. Under legitimate interests we will keep some individual's information beyond this timeframe however this data will be anonymised.

Donors

All donors' records will be retained for 6 years after their last contact with the Society for Mucopolysaccharide Diseases.

Clinical trial participants

All records of personal data relating to clinical trial participants will be retained for 3 years, or as specified by the clinical trial sponsor, after their last contact with Rare Disease Research Partners

Research, survey and study participants

All records of personal data relating to participants in research, surveys and studies will be retained for 3 years, or as specified by the project sponsor, after the end of the project.

Employment

Income tax and NI returns, income tax records and correspondence with the Inland Revenue: not less than 3 years after the end of the financial year to which they relate.

Records relating to events notifiable under the Retirement Benefits Schemes (Information Powers) Regulations 1995, and records concerning decisions to allow retirement due to incapacity, pension accounts and associated documents: 6 years from the end of the scheme year in which the event took place, or the date upon which the accounts/reports were signed/completed.

Statutory Maternity Pay records, calculations, certificates (Mat B1s) or other medical evidence: 3 years after the end of the tax year in which the maternity period ends.

Statutory Sick Pay records, calculations, certificates, self-certificates: 3 years after the end of the tax year to which they relate.

Wage/salary records (also overtime, bonuses, expenses): 6 years.

Disposal of personal and sensitive data

The Society for Mucopolysaccharide Diseases has a responsibility to dispose of personal and sensitive data which has passed its retention date carefully and securely. The following processes must be followed:

- Manual records must be shredded and disposed of as 'confidential waste'
- Any removable or portable computer media such as hard drives as USB sticks must be destroyed under the guidance of IT Mighty.

Document owner

The data controller is the owner of this policy document and must ensure that it is periodically reviewed according to the review requirements contained herein.

The latest version of this policy document dated 08.04.2021 is available to all employees of the Society for Mucopolysaccharide Diseases on the corporate intranet.

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

Name of GCEO: Bob Stevens

Date: 08.04.2021

Document History			
<i>Version</i>	<i>Author</i>	<i>Date</i>	<i>Changes</i>
1.0	Bob Stevens	2 nd June 2018	First version
1.1	Tom Kenny	19 th May 2020	Addition of text regarding Clinical trials and research
1.2	Barbara Cotterell	23 June 2020	Addition of disposal criteria
2.0	Lesley	January 2021	

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

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