



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 Data Retention Periods Relevant to the Business of the MPS Society and its wholly own subsidiary Rare Disease Research Partners - Statutory Requirements are followed where required.

Patient Services

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 consent must be obtained before services can be provided. In this instance we retain data as follows:

| Type of Data | Retention Period |
|--------------------------------|---|
| General case notes | 6 years after the file is no longer active |
| Records relating to children | Until person turns 25 years old – then review |
| Members | 6 years then reviewed |
| Child safeguarding information | Until person turns 25 years old |
| Adult safeguarding information | 6 years after closure of file |
| Anonymised data | Indefinitely |
| Deceased data | Indefinitely |

There may be occasions where for research purposes we may retain some individual's information beyond this timeframe under legitimate interests, in this instance data should be anonymised.

The Society for Mucopolysaccharide Diseases recognises that 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.

Projects & Events

The Society for Mucopolysaccharide Diseases holds both virtual and face to face activities and events in order to support MPS members and their families. Except in the event of any investigations being held, all personal data held in relation to such activities and events will be retained for 1 year.

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 in line with the specification of the project contract. If no retention detail mentioned in the contract personal data will be kept for 3 years after the end of the project.

Employment

| Type of Data | Retention Period |
|--|---|
| Main employment record | 6 years following termination of employment |
| Income tax, National Insurance records and correspondence with Inland Revenue | We retain for 6 years however HMRC will retain permanently |
| 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 | 6 years following termination of employment |
| Statutory Sick Pay records, calculations, certificates, self-certificates | 6 years |
| Wage/salary records (also overtime, bonuses, expenses) | 6 years |
| Records relating to DBS certificate | 6 years following termination of employment |
| Records relating to Life Assurance Policy | At termination of employment |

Medical

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

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Accounting

Accounting records: 6 years

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

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 and 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 21.06.2021 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: 21.06.2021

| 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 | |
| 3.0 | Barbara Cotterell | 21 June 2021 | Complete retention update to match mapping document |

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