



The UK charity for **W**aldenstrom **m**acroglobulinemia

Information and Data Protection Policy for the WMUK Support Line

This policy must be used alongside, and in keeping with, the following policies which can be found in the WMUK Staff Handbook:

- Privacy Statement
- Data Quality and Records Policy
- Data Protection Policy

The term 'service user' applies to anyone who calls the Support Line.

Overview:

Identifiable information will only be held when a service user accesses the Support Line and explicit consent has been gained through a verbal agreement.

This will be discussed at the beginning of each call, and made clear what information is being gathered and the reason why.

If a service user does not wish to have a client record with identifiable information held on them, then WMUK will respect this and still support them with their enquiry but will explain that this may limit the service that we are able to provide.

Identifiable information will only be passed within the charity as required for the management of the Support Line Service, or to meet the service users' explicit needs.

Statistical information relating to the Support Line users is collected for managerial and service improvement purposes and may be shared widely, however this data is anonymous.

Service users' data will not be passed to external organisations without clear written or verbal consent.

However, there are certain circumstances in which WMUK may be obligated to disclose information to other organisations, which are further explained in the '[Confidentiality Policy](#)'.

What Data We Hold:

When using the Support Line, WMUK will only ask service users to supply information that we need in order to provide them with further support or advice that they have requested. We will normally ask for the following details to be provided:

- Name
- Contact Details
- Notes on the call and any relevant background information needed to support the individual effectively.

For monitoring purposes, it may also be helpful for us to know the service users age, year of diagnosis, location, ethnicity, sex, treatment centre and type and how they heard about us.

We will at times collect service user-feedback through a confidential questionnaire so we can see how the service has helped, or any improvements which can be made to help improve the service.

We may also request other information where it is appropriate and relevant.

Access To the Information We Hold:

The service user has the right to request a copy of the information that we hold about them and are entitled to have their personal details removed from our database if they so wish. They should contact WMUK if they wish to do this via email at info@wmuk.org.uk

Keeping Personal Data Secure:

WMUK take our obligation to keep service users' personal data safe and secure very seriously.

- Personal information will be held on Raisers Edge, an electronic client record system in accordance with the data protection law. Access to the system is tracked and monitored by the Database Manager.
- Any inappropriate access to a client record will be treated as a potential serious breach of the charity's data protection policy and may lead to disciplinary action.
- To enable WMUK to deliver a high-quality information and support service we hold both personal and sensitive data of service users of the support line. We do not use

this data for marketing purposes without consent.

Clear and accurate records are a necessity to make a referral to a child protection or adult safeguarding agency – if you believe that someone may be at risk of abuse or in need of further assistance by emergency services.

- Sensitive personal information will only be kept on our client record system for as long as it is necessary.
All emails are kept confidential to WMUK and will be deleted once details have been transferred to Raisers Edge or dealt with.

- To ensure the confidentiality of people contacting us for support, we will not leave answer phone messages when returning calls unless we have been explicitly told this is OK.
Phone numbers are withheld by support line staff when making outgoing calls to service users.

Policy Written: October 2022

Review Frequency: 2 yearly or as required

Reviewed and updated: 30/05/2024