



## **MDS UK Strategic Objectives**

### **December 2022**

**We exist to improve the lives of everybody affected by MDS and CMML.**

**We do this by:**

- **Providing accurate and accessible information**
- **Facilitating patient-to-patient and other support**
- **Advancing the treatment and care of MDS/CMML patients**

### **Our Strategic objectives:**

1. **To ensure all patients, caregivers and families affected by MDS/CMML gain easy and immediate access to the services of MDS UK, as soon as possible after diagnosis:**

*An example of how we will achieve this:*

- Work with NHS, UK MDS Forum, British Society of Haematology, and other relevant organisations to develop and agree a standard procedure for referral of MDS/CMML patients to MDS UK Patient Support Group.

Measurable by: a year-on-year increase in number of members.

2. **Ensure high-quality communications to patients, families, and clinicians**

*Examples of ways in which to achieve this:*

- Review all communications for effectiveness, using specialist communications resources
- Ensure our communications are linked across all platforms, including website, social media, direct mailings etc, and are relevant to MDS/CMML patients, caregivers, and families from a diverse range of backgrounds
- Review our core information annually, updating as necessary

Measurable by: tracking our social media and website engagement; regular user satisfaction surveys.

3. **Provide both bespoke and generic support to patients, carers, and families**

*Examples of ways in which we will achieve this:*

- Ensure every new member is contacted personally by a volunteer supporter within one month of them contacting us
- Recruit a paid Volunteer Co-ordinator to provide professional and administrative support and training to our volunteers/ambassadors

- Organise a minimum of 12 online patient support meetings per year, plus a number of additional specialist-themed meetings with guest speakers, with a particular focus on encouraging new attendees
- Encouraging and supporting patients/families in engaging with IT, and signposting to other organisations providing specialist IT support, 'Buddy' schemes etc.

Measurable by: Monitoring member engagement; recording meeting attendees

#### **4. Continue to support research, on a revised and targeted basis**

*Examples of ways in which we will achieve this:*

- By engaging in PPI (Patient and Public Involvement) work, increasing our capacity and reach
- By participating in research into patient care and QoL (Quality of Life) improvement support
- By increasing our pool of volunteer PPI experts, with an emphasis on recruiting and training newly-diagnosed patients who are better-placed to identify with the needs of other patients with little knowledge about their disease.

Measurable by: keeping and updating a full register of all PPI projects.

**To support these strategic activities, the Charity undertakes to:**

- **Review our organisation's governance, constitution, policies and operating procedures, to ensure they are aligned with the agreed strategy**
- **Review our organisational and administrative capacity, making appropriate investment to ensure it is a) aligned with the agreed strategy and b) fit for purpose**
- **Review and develop our fundraising strategy, to ensure it meets the increased investment level and ongoing expenditure requirements of the charity's agreed 5-year strategic plan**