Myeloma UK Strategy

2019–2023

We aim to Make Myeloma History.

This document outlines our five year plan towards achieving our ambitious strategy to deliver what patients, carers and all those affected by myeloma want.

MyelomaUK

Foreword

Since our establishment, Myeloma UK has made a positive and significant impact by working innovatively, collaboratively and passionately in myeloma research, treatment and support. Throughout this time, we have listened to patients, carers and all of those affected by myeloma, to fully understand their needs and wants from us.

This has underpinned our activities and how we allocate vital funds, helping expedite huge advances in research and treatment over the past five years in particular. These activities have resulted in great progress which have benefitted many. Survival rates are now increasing faster than in most other cancers and patients are living with a far higher quality of life.

These advances have created a sense of optimism and momentum that we must capitalise on. Over the next five years, we can radically improve the outcomes that Myeloma UK delivers for people affected by it.

This report details a strategy for achieving this and outlines how we will use our knowledge, expertise and resources as effectively as possible to bring positive change and work purposefully towards our aim to Make Myeloma History.

Together, our staff and Board have developed a compelling vision, ambitious goals and clear purpose that have shaped the strategy we present here. Our strategy is directed at refining our Research and Services capabilities and deliverables to ensure they align fully with patient needs. We have also explored the evolving external environment we operate in and the enablers who will make the strategy a reality.

Our aims are highly ambitious but are in line with the opportunities, challenges and the responsibility we face as an organisation. I firmly believe this strategy will help those affected by myeloma.

In five years' time I look forward to looking back proudly on what has been achieved as a direct result of implementing this strategy.

Rosmarie Finley
Chief Executive, Myeloma UK

Our strategy in summary

In working to achieve our objectives and outcomes, we will adhere to the following strategic framework.

The framework is summarised opposite and forms the backbone of our approach.

Right: **Myeloma UK Strategy 2019–2023**

Our Mission

Make myeloma history

Our Values

Excellence **Compassion** **Passion** **Collaboration** **Innovation**

Our Goals

Support and improve care, experience and treatment for patients

Find answers: invest in myeloma research

Lead change: give myeloma the prominence needed

Enablers

People

We will have diverse, competent and skilled workforce.

We will invest in development of volunteer workforce.

At all levels of organisation, our people feel valued and motivated.

Resources

We will always look for efficiencies where possible and continue to ensure we use our resources in the most optimal way.

We will grow and diversify our portfolio of income.

Governance

We will continue to ensure our policies, procedures and ways of working are safe, effective and compliant to legislation and good practice.

The challenges we face

There is increasingly tough competition from other charities regarding income generation, positioning and influence. As of June 2018, 19p of every £1 donated in the UK goes to 13 charities – meaning it's hard for Myeloma UK to break into this market.

Donation levels are stagnating in the UK with just 0.4% of household expenditure being charitable donations. This could be attributed to a decline in public trust and confidence in charities following series of scandals.

Brexit continues to be an ongoing uncertainty potentially impacting negatively on research funding and capacity. Additionally, there could be a negative impact caused by Brexit on patient access to new treatments in the diminished UK market.

The economic picture remains fragile with strengthening of key global markets such as the USA being offset by uncertainty around Brexit. The vast majority of economic analysts highlight that anything other than remaining in the Single Market and the Customs Union will have a negative impact on the UK economy as a whole.

Charities are mindful that the potential fallout from leaving the EU (without remaining in the Single Market and Customs Union to continue with free trade) could result in falls in the value of sterling, which could see inflation rise higher than the government's 2% target. This would erode disposable income for UK households meaning less opportunity for discretionary spending. Brexit may also change demographics in the UK, notably in context of ethnicity profile, which, due to higher incidents of myeloma in certain ethnic groups, could directly influence the number of people who would engage with the organisation.

Economists highlight that, due to business cycles which are typically considered to last between five and seven years, we are probably closer to the next recession than we are away from the 2009 downturn. Additionally, taxation levels and further increases in the Bank of England base rate may mean people are less able to support charities.

Despite not being funded directly by the Government, Myeloma UK works with other organisations who are. Consequently we could be affected by actions of the Government. Changes to the Government budget directly impacts on funded activities such as the NHS, which could impact our organisational objectives such as earlier detection and improved treatment. With collaboration being one of the five organisational values of Myeloma UK, there is an importance placed on working closely with other institutions and organisations and these collaborative efforts should help to achieve improved business efficiencies, allowing for improved results for patients, carers and all stakeholders.

Another looming challenge the UK faces is the increased pressure of an aging population; putting strain on services and infrastructure. This could impact directly on the work of Myeloma UK as, given the likelihood of myeloma increases with age, there may be more people requiring the services that the organisation provides.

Considering the challenges we face, we have made it a priority in to expand our reach and will continue to build upon this to improve our positioning and influence, delivering more for those affected by myeloma. We will continue to develop strong relationships with our donors. In addition, through a stronger connection to key stakeholders, such as support group leaders, we aim to expand our donor pool, which will lead to more stabilised income in a weaker market.

Our objectives: Health Care Advocacy Services

It is important to us to assist people affected by myeloma and related conditions (such as AL amyloidosis, smouldering myeloma and MGUS) to improve both their experience and their quality of life, as this is one of the key reasons why Myeloma UK was established 21 years ago.

We aim to:

- Inform, educate, support and reduce feelings of anxiety and isolation in patients and their families and carers
- Facilitate timely diagnosis and high standards in delivering treatment and care
- Improve equity, inclusiveness, engagement and reach across various audiences

We plan to continue this work under two broad headings:

- Patient and Carer Information and Support Services
- Services and Resources for Healthcare Professionals

As current leaders in this field, we aim to further develop and provide a range of high quality information and support services to patients, family and carers – whenever they need it. This includes clinical information, as well as emotional, social and practical support to help people deal with a diagnosis and find practical ways to live well. We strive to help people navigate the complexities of the healthcare system and make informed decisions about their own treatment and care.

The patient and carer services aspect is complemented by developing and delivering a range of information and services for healthcare professionals. These services facilitate awareness and education in order to enhance and improve diagnosis time, understand patients' needs and preferences, and drive improvements in treatment standards and care provided. Furthermore, it is recognised that healthcare professionals are a key asset in signposting patients to Myeloma UK.

Our intention is to maintain engagement with existing service users as well as design and deliver new programmes and formats of services to reach a wider audience.

We intend to realise our **Support and Improve Care, Experience and Treatment for Patients** goal by delivering work across the following work-streams:

- Patient Information (to also include families, carers and healthcare professionals)
- Infoline and associated programmes
- Infodays and related events
- Support Groups
- HCP educational resources
- Myeloma UK Early Diagnosis Programme
- Clinical Service Excellence Programme (CSEP)
- Myeloma UK Representatives

We have set ambitious targets as we know this is the only way we will see a real and lasting positive impact for patients. There are around 50 detailed target types across the work-streams, with identified associated key performance indicators to help us track progress over the next five years. There are 18 key outcomes across the programmes of work that will have a lasting and positive impact on patients' quality of life and the quality of care they receive.

Our objectives: Research

There has been much progress made towards the understanding and treatment of myeloma and related diseases. Myeloma in particular has seen increases in survival time in tandem with the use of newer treatments, developed through research. However, it remains a complex, highly variable, relapsing/remitting and incurable cancer. Living well and living longer are both key; unmet patient needs, which means there is still much for research to discover and develop. Crucially, patients must be able to benefit from these achievements. To address and align these points, Myeloma UK will build upon existing strengths and prior successes to expand in line with patient needs, external opportunities, and ambitions for the charity. Our second Strategic Goal is to **Find answers and invest in myeloma research**. This goal will be achieved across several key themes:

- **Translational Research:** to increase our understanding of underlying disease mechanisms and to apply this knowledge towards patient benefit
- **Clinical Trials:** our pioneering Clinical Trial Network will continue to deliver innovative, patient-centric early phase trials, allowing patients access to novel treatments and to provide an evidence-base for later phase studies
- **Patient Insight and Data:** our Health Services Research will continue to provide robust insight into the diversities of patient experience, need and preference so these can be understood and addressed through better research, care, treatment and support. In addition, we aim to develop the first Myeloma Patient Registry in the UK. This could provide real-world evidence on treatments, the systematic reporting on patient experience and clinical outcomes – and highlighting variance/inequalities in access to treatment and best practice
- **Prevention and Diagnosis:** we aim to develop a programme for secondary prevention research focussing on transitions from MGUS and smouldering myeloma, and to support research into early and better diagnosis

Research will be delivered through a combination of longer-term strategic investment programmes and over time, shorter-term, open grant funding calls to address the thematic priorities set out in this Strategy.

Whilst the main focus is on myeloma, restricted income for the related diseases will be sought to develop specific research programmes in those areas.

Research and innovation in new treatments are of no value to patients if they cannot be accessed. Myeloma UK will build on its strong reputation and unique position to represent fully the priorities and interests of patients and family members in our **Patient Advocacy** strategy, ensuring that their voice is heard and acted on by decision and policy makers.

Supported by our Patient Insight and Data research theme, we will use measured, patient-centred evidence-based approaches with all key stakeholders: patients, innovators (e.g. Pharma), Health Technology Assessment (HTA) bodies such as NICE, NHS Commissioning bodies and other organisations with common interests, including third sector alliances.

Our Patient Advocacy work is a key driver of our third Strategic Goal to **Lead change: give myeloma the prominence needed** so that the needs and interests of patients are represented and met. This will include working with policy makers and those in a position of influence, driving thought leadership in a fast-moving and challenging health policy environment

Our enablers

Our enablers are essential for us to deliver successful outcomes.

People

We will have a diverse, skilled and competent workforce who feel valued and supported at all levels.

Myeloma UK has developed great experience over our 21 years in delivering excellence. Some of this is represented in the way we do things; the service we provide to patients, families and carers, the processes and collective knowledge we have developed. We will ensure we have a loyal and highly committed workforce at all levels within Myeloma UK. We must make sure that we continue to have the right people, with the right skills, competencies and values to help us stand out and to develop into the future. We will ensure that all staff understand where their role fits in the organisation and the value that it adds for patients, families and carers.

Myeloma UK will build a new volunteer network to provide benefit and service to patients, families and carers. We know that many people would value support received from volunteers and that volunteers can be integral to helping Myeloma UK achieve our strategy.

Related Objectives:

- HR will provide a strategy to develop a flexible and diverse workforce to ensure we have the required skill set
- Conduct a training needs assessment to identify the current skill set and ensure that staff are trained to meet the needs of the organisation
- Coach, develop and support staff to reach their full potential
- Retain and recruit high quality employees
- Establish a network of volunteers and volunteer programme

Resources

We will maximise our income to ensure resources are available to meet our needs.

In order to achieve our goals we must increase the resources available to us and raise an additional £10 million over the next five years. We will invest in our fundraising to ensure our resources match our ambitions and enable delivery of our strategy. We will ensure financial stability and long-term viability by investing in our capacity to raise funds and continuing to ensure that our reserves policy is always met.

We will support our fundraising in a range of ways, including investing in areas of growth and diversity. We will implement a fundraising strategy to achieve and grow our income through areas such as national campaigns, regular donor giving and a legacy program.

Related Objectives:

- We will increase our fundraising by diversifying and growing our donor base ensuring a year on year increase which is sustainable
- We will develop new partnerships which will broaden our supporter base and develop new audiences
- We will further develop our program of legacy donors to sustain and increase legacy income
- We will seek new income streams including merchandise, retail and commercial opportunities

Our enablers

Finance

We will use our resources in the best possible way to ensure maximum efficiency.

It is important that we respect the support and trust of our donors and repay that trust by making sure that every penny is well spent. We will manage our resources to ensure that we achieve the greatest impact, keeping our work efficient and effective.

It is important that we have a solid structure with robust systems, procedures and controls from which to operate. It is therefore vital that finance maintains internal controls and ensures that a robust financial and non-financial reporting mechanism is in place based on key indicators to measure success against the strategic plan.

Related Objectives:

- Ensure robust systems and controls are in place to match the strategic plan
- Drive cost control to maximise operational efficiency, ensuring non-charitable spend is kept to a minimum
- Ensure a practical and robust disaster recovery plan is in place
- Finance will provide timely and accurate management reporting, financial accounts and financial and business support to all departments

MAKING MYELOMA HISTORY

For further information on our strategy please contact us:

fundraising@myeloma.org.uk
0131 557 3332

Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG
0131 557 3332 myelomauk@myeloma.org.uk

myeloma.org.uk

myelomauk @myelomauk @MyelomaUK myeloma-uk

Myeloma UK is a registered charity no. SC026116