

# Data Officer

Myeloma UK

April 2024

## Welcome

Thank you for your interest in Myeloma UK.

This is a very exciting time to join our team as Myeloma UK is at a key point in our charity's history. Having successfully served our community for 25 years, we are now looking forward to how we can adapt to the changing needs of myeloma patients and their loved ones.

When Myeloma UK was founded the life expectancy for a myeloma patient was between 12 and 24 months. There were no bespoke myeloma treatments available on the NHS, there were big gaps in our knowledge about the disease and getting the latest evidence-based information about myeloma was anything but easy. Today, the life expectancy has quadrupled to between four and eight years, with three out of ten patients living for ten years or more after their diagnosis – and some for much longer. There are now nine myeloma drugs in active use that can be delivered over 12 different combinations, we have funded over £19m of innovative myeloma research and for over two decades we have provided a range of patient support services and information which have been a lifeline for thousands.

We have come a long way. And yet, myeloma is still an incurable blood cancer. We still see one-third of patients being diagnosed at a late stage and in an emergency setting. And we now face new challenges as we work to give our community an empowered present and a hopeful future. With some patients living longer, we also need to ensure they live well with myeloma.

We are passionate about driving positive change for those effected by myeloma and committed to fostering a supportive culture of learning and innovation.

We look forward to hearing from you!

Yours sincerely

A handwritten signature in black ink that reads "Sophie Castell". Below the signature is a long, thin, curved line.

**Dr Sophie Castell**  
Chief Executive

## Our long-term ambition

Make myeloma history

## Our purpose

To give every patient an empowered present and a hopeful future

### In 2022



Our income for the year was £5.2m

£5.2m



Our expenditure on meeting the needs of people affected by myeloma was £5.2m



£1.8m

Our expenditure on research totalled £1.8m



From every £1 of expenditure, 81p was spent on improving the lives of people affected by myeloma

## Our strategy and work

Myeloma UK works to four strategic cornerstones.



**Diagnose**  
myeloma earlier

### We will reduce the impact of myeloma and related conditions on people's lives.

- Better patient outcomes are heavily dependent on identifying myeloma before symptoms develop and we work to raise awareness of myeloma with healthcare professionals and the general public.
- We lead a unique early diagnosis working group that brings together clinical experts to address the challenges in identifying this complex cancer. We will evolve this to invest in vital research to examine how myeloma develops through each stage.



## **Transform**

the patient experience.

**We will identify unmet need, improve outcomes, and ensure equal access to patient-centered treatment and care for patients with myeloma and related conditions.**

- We campaign for patient access to the latest treatments via the NHS through our sector-leading patient advocacy program and provide award-winning information and support services to the myeloma community.
- We will represent patients in every relevant drug assessment and work to have patient preference integrated into the drug evaluation process. We will evolve our information and support services to provide mental health and wellbeing tools and extend the support hours we offer.



## **Discover**

and share knowledge

**We will pursue lasting and transformative scientific discovery in myeloma and related conditions.**

- Our uniquely focused research program works with partners including the Institute for Cancer Research and the Structural Genomics Centre at Oxford University to drive understanding into the causes and treatment of myeloma. We are committed to the principles of open science.
- We will accelerate the development of the most promising new treatments by investing in early stage clinical trial design through our Clinical Access and Research Program (CARP) run in partnership with the University of Leeds and the UK Myeloma Research Alliance. We will set at least two new trials per year through CARP to provide patients with early access to novel therapies, up to ten years ahead of the NHS.



## **Influence**

positive change in care

**We will build the optimum model of care for myeloma patients and patients with related conditions through leadership and collaboration.**

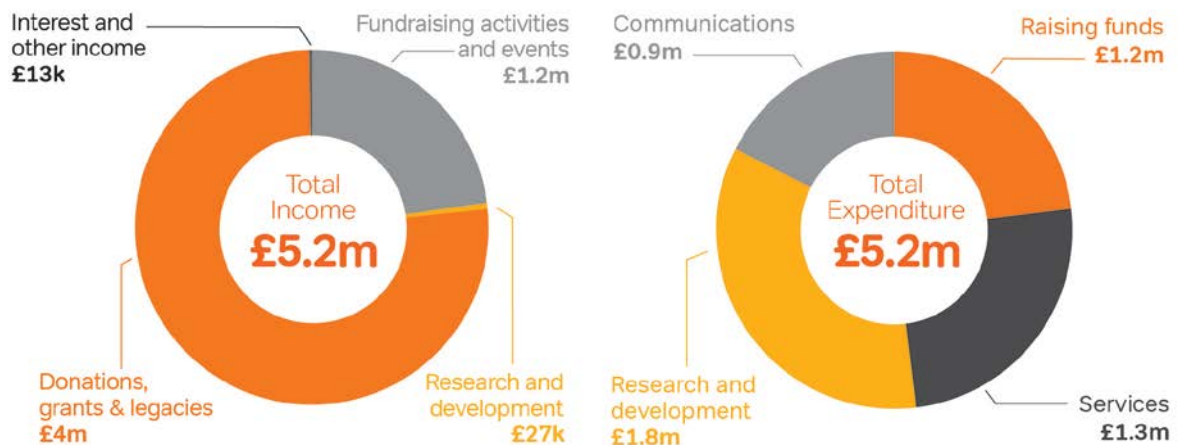
- We invest in the lifetime of the patient journey by operating a best practice accreditation program for hospitals and providing educational and training materials to the wide range of healthcare professionals who treat myeloma patients and those with related conditions. Our health services research program quantifies patient experience and need to change how patient care is designed, delivered and funded.
- We will create a universal experience of myeloma care through our Clinical Services Excellence Program and integrate patient preference into healthcare service design. We will influence the policy making process to ensure the needs of myeloma patients are understood and met.

## Funding our work

Myeloma UK is a fundraising organization with income generated from voluntary fundraising, grants and trusts, philanthropy, and some trading activities. We rely on the generosity of our donors to enable us to run our life-changing programs.

We have ambition to grow our fundraising substantially over the next three years to deliver the change myeloma patients need. Our strategic priorities are:

- Recover our pre-pandemic income by 2023 and pursue an ambitious and sustainable growth five-year strategy to increase income
- Diversify our income streams, developing our high-level donor and trust and foundation activities
- Embed fundraising across the whole organization.



**Income & Expenditure for the 12 months to December 2022**

## Our values



### We strive for **Excellence**

We constantly strive for excellence in everything we are involved with, helping us achieve consistently high standards while offering well informed support. We have expert knowledge, delivering quality in everything we do.



### We are **Compassionate**

Our understanding nature underpins all conversations, meetings and interactions. This warmth helps us empathise with people in difficult situations, offering support while being thoughtful and considerate colleagues.



### We are **Passionate**

Our passion encourages us to go over and above, channelling our energy positively to make significant, measurable progress. We believe in what we do. Our desire to find a cure is unstoppable, as is our drive to help those affected.



### We are **Collaborative**

We are united behind our goal of finding a cure for myeloma. To achieve this, we work with and support a wide variety of stakeholders to drive progress. This collaborative approach empowers us to work as a team, share progress, share knowledge and involve the right people.



### We are **Innovative**

We are always searching for new ways to challenge myeloma. Our work progresses new drugs and treatments, influences policy and encourages positive change. Our ability to look at situations from a variety of perspectives allows us to explore new avenues and find the best ways to support the people we interact with.

## Job Description

<b>Post</b>	Data Officer
<b>Job Ref</b>	C/18
<b>Location</b>	Edinburgh
<b>Department</b>	Communications and Brand
<b>Reporting to</b>	Head of Data Management
<b>Responsible for</b>	This post has no direct reports

### Job Summary

As a Data Officer at Myeloma UK, you will play a pivotal role within the data team as we embark on supporting the charity in delivering on a new strategy. The role will be varied from ensuring our data is handled with the utmost care and in compliance with data protection best practice to rolling up your sleeves with database management, data cleaning, reporting and analysis.

As a member of the Communications and Brand Department, the Data Officer will contribute towards the planning and delivery of the business's strategic, operational, and departmental plans.

### Key Deliverables

#### 1. Data Protection and Privacy

- Work with colleagues across the charity as they review and plan their processing of personal data by supporting them to complete Data Privacy Impact Assessments (DPIAs).
- Manage the recording of data assets to ensure we keep our data safe and secure. You will oversee the maintenance of our Records of Processing Activities (RoPA) log.
- Oversee the monitoring of communication preference collection to keep on top of our compliance with Privacy and Electronic Communications Regulations (PECR) and UK General Data Protection Regulation (UK GDPR).
- Develop and implement data protection processes that everyone can follow.



- Write, review, and edit standard operating procedure (SOP) guides to enable consistency in our practice. Support colleagues to provide a high level of supporter and patient experience and care

## **2. Data Management**

- Support the Head of Data Management in ensuring that data held, collected, and processed is accurate and well managed across all charity systems.
- Improve the data flows from third party software to our CRM using import mapping software and supporting colleagues with its functionality through training and support.
- Assist the Finance Team with gift processing, ensuring the database is up to date and accurate

## **3. Data Strategy**

- Play a key role in shaping and delivering on our new data strategy
- Develop and manage the programme to improve the charity's data maturity through staff training programmes and implementing best practice
- Work collaboratively across the whole charity to build relationships and collect user requirements for new and existing data products. Lead by example as we move towards creating a culture where we use data to make informed decisions

## **4. Training, Reporting and Analysis**

- Provide training and ongoing support to colleagues on CRM functionality as well as general data skills
- Collaborate with colleagues to create dashboards and visualisations that make data easy to understand and act upon
- Spot trends and offer your insights to help boost our fundraising and operational strategies.
- Support staff to integrate the CRM into office working practices, particularly the recording of supporter/patient communications and notes
- Promote the benefits of the data across the charity, encouraging wider and more effective use
- Demonstrate a commitment to ongoing learning and development and to participate in any training relevant to the role

## 5. General

Continuous improvement, developing skills, adhering to organisational quality standards, and teamwork underpin all roles at Myeloma UK.

General responsibilities include:

- Adopt the Myeloma UK principles of quality management
- Be attentive to and implement organisation brand and style guidelines
- Participate in team meetings and work together with colleagues to maintain and improve knowledge and skills
- Act as a source of information and support to colleagues throughout the organisation
- Build productive working relationships with external advisers to maintain and enhance their commitment to Myeloma UK
- Demonstrate a commitment to ongoing learning and development and to participate in any training relevant to the role
- This role will require some essential travel throughout the UK; therefore, the post holder must be willing to travel. Regular travel to Edinburgh if based elsewhere will be required
- Undertake such work as may be appropriate to the post

This job description is not exhaustive. It merely acts as a guide and may be amended to meet the changing requirements of Myeloma UK at any time after discussion with the post holder.

## Person Specification

Area	Essential	Desirable
<b>Qualifications &amp; Experience</b>	<ul style="list-style-type: none"> <li>• Proven experience of relational databases and their relevance in a fundraising or marketing environment</li> <li>• Experience of implementing database, quality control and administrative procedures</li> <li>• Experience of working with internal and external stakeholders at all levels</li> </ul>	<ul style="list-style-type: none"> <li>• Experience of data transformation using any tool</li> <li>• Experience of communicating, supporting, and training colleagues at all levels if digital literacy</li> <li>• Experience of supporting a wide range of stakeholders</li> </ul>
<b>Knowledge</b>	<ul style="list-style-type: none"> <li>• Advanced knowledge of Blackbaud's Raiser's Edge (or similar)</li> <li>• Data analysis and transformation</li> <li>• Data visualisation and how to visually represent data clearly</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of charity data management incl. gift aid, direct mail management, and working with special category health (patient) data</li> <li>• Knowledge of data protection law and issues</li> </ul>
<b>Skills</b>	<ul style="list-style-type: none"> <li>• Numerate and with strong IT skills</li> <li>• Effective communication skills, both verbal and written</li> <li>• Ability to manage a busy and varied workload, working methodically and paying attention to detail</li> <li>• Ability to build complex database queries</li> <li>• Ability to problem solve and manage own workload</li> <li>• Ability to manipulate and analyse data</li> </ul>	<ul style="list-style-type: none"> <li>• Ability to author reports designed to monitor the progress of the fundraising plan</li> <li>• Confident in implementing measures to ensure accuracy, and quality of data</li> </ul>

## Terms and Conditions

<b>Post</b>	Data Officer (full time, permanent)
<b>Salary</b>	£29,744 - £32,419
<b>Probation period</b>	Three months
<b>Hours of work</b>	<p>The standard working week comprises 35 hours, Monday to Friday. Myeloma UK operates a flexitime scheme, and details will be provided by the Head of HR and Operations.</p> <p>The post holder will be expected to assume duties outside working hours to support the delivery of their role and the operation of the organisation when required.</p>
<b>Holidays</b>	Full-time holiday entitlement is 30 days per calendar year, plus 6 public holidays.
<b>Pension scheme</b>	Myeloma UK complies with its auto-enrolment obligations and, subject to matched employee contributions, offers a 7% pension contribution to all staff.
<b>Premises</b>	Myeloma UK is situated at 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG.

## Join us!

At Myeloma UK, we are committed to bringing together the best and brightest people across the whole organisation. We are interested in people who have helped charities and organisations achieve their ambitions, be that through professional or lived experience. We know that it is only by bringing multiple talents into a team that we can achieve change, so we would like to hear about what makes you exceptional – your skills, your interests, your experience, and your values. We are committed to reflecting the whole myeloma community in our structure, so we particularly encourage applications from black and ethnic minority communities and from people with disabilities.

Myeloma UK offers its employees a range of benefits including a pension salary exchange scheme, flexitime, flexible working from home with hub-based office working, health plan and holiday purchase scheme and we are committed to providing learning and development opportunities for all our employees.

As part of any recruitment process, Myeloma UK collects and processes personal data relating to job applicants. Myeloma UK is committed to being transparent about how it collects and uses that data and to meeting its data protection obligations. You can read more about how we do this here: <https://www.myeloma.org.uk/wp-content/uploads/2024/04/Myeloma-UK-Job-Applicant-Privacy-Notice.pdf>

Diversity, equality and inclusion are at the core of who we are and our commitment to these values stretches across all our work. We know that having varied perspectives helps generate better ideas to solve the problems of a changing and increasingly diverse world. We want to ensure we have a diverse team, and when we recruit we welcome applications from people of colour, LGBTQ+ people and disabled people.

Myeloma UK funds research into myeloma and is a member of the Association of Medical Research Charities. As part of this we have a statement on our website with our position that we support animal use in research in an essential, appropriate and ethical way. For further information please go to <https://www.myeloma.org.uk/wp-content/uploads/2020/05/Animal-use-in-Research.pdf>

## How to apply

If you think you would be a great fit for the role, please submit a copy of your CV together with a supporting letter to [jobs@myeloma.org.uk](mailto:jobs@myeloma.org.uk).

Your letter should include the following:

- Why you are applying for this post
- How your skills and knowledge meet the requirements of the role
- How your experience and expertise can support and reflect our values
- Whether you currently have the **right to work in the UK**

**Please note that only CVs accompanied by a supporting letter will be considered.**

Applications close on 13 May 2024.

Interviews will be held w/c 20 May 2024.

Appointment will be subject to receipt of satisfactory references and right to work checks.