Recruitment

Pack

Patient Information Officer

Myeloma UK

May 2022

Contents

Welcome

Thank you for your interest in Myeloma UK.

Myeloma UK invests in driving better patient outcomes through a comprehensive early diagnosis program, cutting-edge research, sector-leading treatment access, award-winning information and support programs, and pioneering healthcare services improvement. Our community consists of the 24,000 people living with the incurable blood cancer myeloma, as well as those with related conditions including MGUS (a non-cancerous condition that can increase the chance of developing myeloma), smouldering myeloma (an early form of myeloma) and AL amyloidosis (a rare build-up of protein occasionally associated with myeloma). Including our patients with related conditions, the population we represent is over 63,000 people.

Our long-term ambition is to make myeloma history, but we recognize that is a challenging process. As we work to that ambition, we are committed to providing every patient with an empowered present and a hopeful future.

Our current income is c£4.8m. The pandemic has presented challenges but, with a lot of hard work, our teams have delivered on budget. We are in a good position financially, so there is a sound platform from which to build.

We are committed to ensuring that patients receive more effective treatments, enjoy better outcomes, and have more years with a life they love. A positive, empowering culture is important to us, and we like to have fun along the way.

Our **long-term ambition**

Make myeloma history

Our **purpose**

To give every patient an empowered present and a hopeful future

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In 2020

Our income for the year was £4.7m

Our expenditure on meeting the needs of people affected by myeloma was £3.2m.

Our expenditure on research totalled £0.9m

From every £1 of expenditure, 80p was spent on improving the lives of people affected by myeloma.

COVID-19

As a cancer charity, COVID-19 has had a significant impact on our community. Myelomapatients are ten times more likely than a member of the general public to catch a virus such as COVID-19 and, because of the way their cancer develops and is treated, are categorised as extremely clinically vulnerable. In 2020, the pandemic impacted the treatment of over 40% of our patients, and every patient has had to accept changes to the way they connect with their clinical teams and the way they live their lives.

In light of these significant additional pressures on our community, we reviewed our strategy and re-set our strategic priorities according to on-going need. This enables us toaddress the serious emerging concerns of:

- Delayed diagnosis of new myeloma patients and the impact of that delay on theirclinical outcomes
- A shortfall in cancer research funding
- Geographical inequalities in provision of treatment and care
- Pressure on the NHS and on health policy design and delivery

Our **ambition for 2021**

The COVID-19 pandemic has led us to refocus and refresh our strategy, but our purpose remains the same: giving every patient an empowered present and a hopeful future.

Our work in 2021 and beyond will deliver against four strategic cornerstones:

Diagnose
myeloma earlier

We will accelerate work on earlier detection and diagnosis to make the greatest impact on the length and quality of lifefor myeloma patients and those with related conditions.

- The Myeloma UK Early Diagnosis programme identifies and addresses barriers to earlier diagnosis
- The Myeloma UK Early Diagnosis Working Groups develop tools and education materials to speed up detection, referral and diagnosis at GP-level
- We will establish the Myeloma UK Early Diagnosis Research programme to better understand how myeloma develops and identify patients at risk

Discover
and share knowledge

We will drive scientific breakthrough into the cause and treatment of myeloma and related conditions to increasepatient survival and improve patient experience.

- Myeloma UK funds translational research at the ICR to accelerate the development of personalised medicine to myeloma patients
- Myeloma UK funds the UKMRA Myeloma UK Concept & Access Research Programme (CARP) to create new clinical trials and give patients early access to novel treatments
- Myeloma UK supports the development of future research leaders by funding a Clinical Research Fellowship at the University of Leeds and the development of our early care research programme, fostering interest in myeloma as a focus of future research
- The Myeloma UK patient data project enables better insight and evidencing of patient need and changes to policy, treatment and care
- Myeloma UK's Health Service Research identifies unmet need and patient preferences to inform change in healthcare policy and delivery

Transform

the patient experience

We will partner with patients to understand and meet their needs and build equal care for all.

- Myeloma UK puts patient need and experience at the heart of drug appraisals to make sure that patients can access new treatments
- Myeloma UK drives excellence in patient-centred hospital care through our Clinical Services Excellence Programme (CSEP)
- The Myeloma UK Myeloma Academy and Myeloma Nurse Learning Programme educate healthcare professionals to ensure that patients receive the best care informed by the latest learnings
- Myeloma UK has the most comprehensive library of patient information on myeloma and related conditions, helping patients to understand and be in control of their decision-making
- Myeloma UK offers specialist, tailored support to the whole myeloma community through our Myeloma Infoline and Ask the Nurse email service
- Myeloma UK delivers a range of digital and physical events, directly connecting patients and families to expert analysis, advice and support
- Myeloma UK partners patients to provide a UK-wide network of Support Groups, reducing isolation and offering friendship to the whole myeloma community
- Myeloma UK will establish a volunteer peer to peer support service to bring together shared patient experiences and practical tips for living with myeloma and related conditions

Influence

positive change in care

We will give a voice to patients and ensure that myeloma is not considered a second-class cancer.

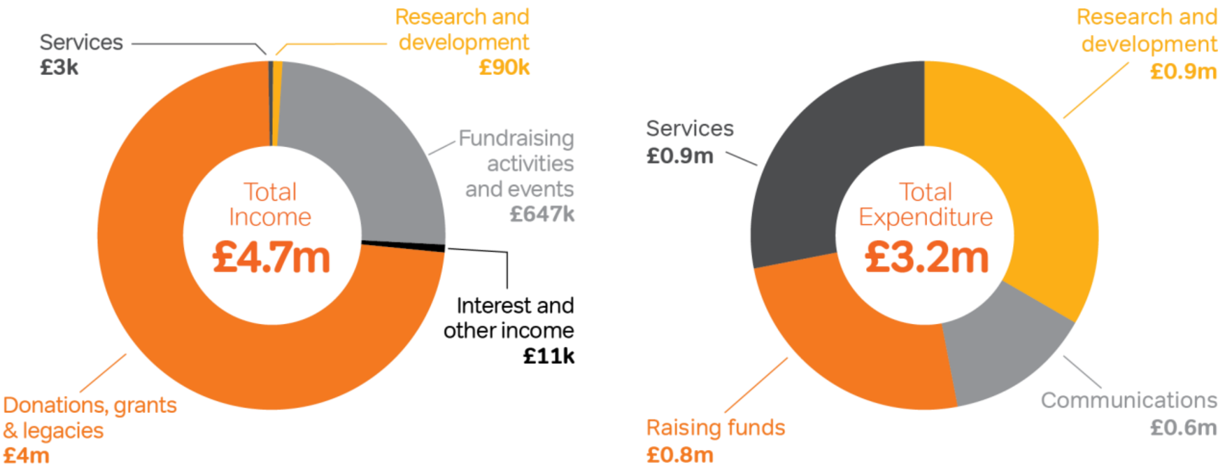
- Myeloma UK works to shape government policy across the four UK nations to recognise the needs of patients with myeloma and related conditions and create positive change
- The Myeloma UK Advocacy Panel ensures patients speak directly to decision makers in NICE and government
- The Myeloma UK Patient and Carer Research Panel integrates patient need into research design and policy development
- Myeloma UK's Healthcare Advocacy Service programmes drive improvements in clinical practice and patient-centred care
- Myeloma UK works with colleagues and stakeholders who share our vision for myeloma and blood cancer care and are committed to delivering positive change for patients

Funding our work

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

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

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



Income & Expenditure for the 12 months to December 2020

Building our brand

Myeloma UK is a trusted brand with patients, supporters, research partners and healthcare professionals. Our current audience is a limited one and committed to us butoften supports more than one blood cancer charity, hospital or hospice.

We need to grow greater recognition of our brand and the work the charity does with boththe general public and decision makers, as well as continue to explore innovative and cost-effective ways in which we can grow brand reputation and reach without losing the sense of trust our community has given us.

Measuring our success

We need to be able to demonstrate and understand the difference we make in order tocontinue to innovate our programmes and attract continued funding.

We measure our success via:

- Patient experience
- Retention of supporters
- Reach of materials and marketing campaigns
- Delivery of projects
- Growth in income

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

Post	Patient Information Officer (permanent, full time)
Job Ref	S/22
Location	Home-working with some office hub-based days
Department	Healthcare Advocacy Services Directorate
Reporting to	Head of Patient and Carer Information and Support
Responsible for	This post has no direct reports

Job Summary

This role provides a rewarding opportunity to develop the range of patient information that Myeloma UK produces for myeloma patients, family members, carers and friends.

Our information covers a wide range of topics from diagnosis, treatment and care, and living well with myeloma. Information is available both online and in print. The variety offers an opportunity for the post holder to work with a range of stakeholders and topics.

The Patient Information Officer will maintain, develop and deliver accurate printed and online information (written and audio/visual) on myeloma and its related conditions for patients, their family and carers. They will take complex medical and scientific language and translate it into clear and concise information for a patient audience.

The post holder will work with colleagues to ensure close communication and sharing of information across the organisation and report progress regularly to their line manager.

As a member of the Healthcare Advocacy Services Team, the Patient Information Officer will contribute towards the delivery of the business's strategic, operational, and departmental plans.

Key Deliverables

Patient, family and carer information

1. Build and maintain a high level of knowledge of myeloma and its related conditions, including AL amyloidosis, smouldering myeloma and MGUS

2. Build and maintain knowledge of best practice in information provision to patient, family and carer audiences

3. Review and update existing publications and online information in line with Myeloma UK policy and brand and style guidelines

4. Develop new print and online information for patient, family and carer audiences, including publications, magazine articles and website content, complying with Myeloma UK style and brand guidelines

5. Follow procedures and processes for producing information in line with the PIF TICK

6. Support the development of digital projects as required, which may include assisting the production of videos or tools/apps as planned

7. Assist in the development of content for information events

8. Work with the Senior Patient Information Officer to maintain the volunteer-based patient information review panel

9. Assist in the collection and analysis of feedback from our audiences about patient information

10. Assist in the assessment of the impact of patient information programmes and resources and collate evidence to support impact analysis, including patient stories, case studies, surveys and questionnaires

11. As part of the Patient Information team, help to develop approaches to increase reach across diverse groups of people affected by myeloma and related conditions, and identify gaps in our current information provision through surveys and other research

12. Work with Communications colleagues to ensure myeloma information is proactively distributed to myeloma patients, family and carer audiences, as well as the healthcare professional audiences. This will include providing content for social media and e-newsletters

13. Collect agreed KPIs and prepare and present regular updates to highlight the progress and performance of agreed project deliverables

14. Ensure appropriate details are being recorded on the RE system complying with relevant GDPR guidelines

15. Proactively research topics and share knowledge and understanding with team members

Patient and carer information and support team

1. Answer the Myeloma Infoline when the Myeloma Information Specialists are not available, answering queries within knowledge level and taking messages for more complex ones

2. Cover Services Administrator responsibilities as and when needed

3. Represent Myeloma UK at conferences, Infodays and other information events, Support Groups and other relevant meetings and be able to present about your work and Myeloma UK to inform, raise awareness and offer support as required

General

Continuous improvement, developing skills, adhering to organisational quality standards, and team-work underpin all roles at Myeloma UK. General responsibilities include:

1. Adopt the Myeloma UK principles of quality management

2. Be attentive to and implement organisation brand and style guidelines

3. Participate in team meetings and work together with colleagues to maintain and improve knowledge and skills

4. Act as a source of information and support to colleagues throughout the organisation

5. Build productive working relationships with external advisers to maintain and enhance their commitment to Myeloma UK

6. Demonstrate a commitment to ongoing learning and development and to participate in any training relevant to the role

7. 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

8. 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
Qualifications & Experience	- Educated to degree level in a biology/medical-related subject - Experience of writing information materials for a range of audiences - Experience of producing information for different channels (online and in print) - Experience of managing own workload to meet deadlines	- Experience of writing information materials for patients, family and carers - Experience of working directly with patients, family members, carers - Experience of content development for information events e.g. seminars
Skills & Abilities	- Knowledge of the stages involved in producing information including research, writing, external review and liaising with designers - The ability to convey complex medical and scientific information in lay terms - Excellent writing, copy editing and proofing skills (English) - Excellent attention to detail and high level of accuracy - IT skills with experience of using Microsoft Office - The ability to liaise with a range of internal and external stakeholders effectively - The ability to research topics and identify key information	- General health and cancer knowledge - Familiarity with short surveys and basic analysis of qualitative and quantitative data
Other	- Self-motivated and able to work independently	

	• Dedicated team player • Ability to manage a wide range of tasks and work well under pressure • Desire to continuously learn and build specialist knowledge • Commitment and desire to make a difference • An ability and willingness to work out of the office across the UK as required • Willingness and ability to undertake occasional weekend and evening work, when required	

Terms and Conditions

Post	Patient Information Officer – permanent, full time
Probation period	Three months
Salary	£25,750 – £28,066
Hours of work	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. The post holder will be expected to assume duties outside working hours to support the delivery of their role and the operation of the organization when required.
Holidays	Full-time holiday entitlement is 30 days per calendar year, plus 6 public holidays. Part-time holidays will be calculated pro rata.
Pension scheme	Myeloma UK complies with its auto-enrolment obligations and, subject to matched employee contributions, offers a 5% pension contribution to all staff.
Premises	Myeloma UK is situated at 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG.

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.

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 18 May 2022

First interviews will be held virtually w/c 23 May 2022

Appointment will be subject to receipt of satisfactory references.

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: www.myeloma.org.uk/jobapplicantprivacy.

Note: Myeloma UK fund research into myeloma and are 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