Job Description

Post	Head of Patient Advocacy (permanent, full-time)
Job Ref	R/1
Location	Flexible
Department	Research & Advocacy
Reporting to	Director of Research & Advocacy
Responsible for	Access Manager, Policy Manager, & two Senior Policy Officers (x4 FTE reporting line)

Job Summary

Reporting to the Director of Research and Advocacy, the Head of Patient Advocacy is responsible for leading Myeloma UK's work to make the patient voice count with decision makers.

As a member of the Research and Advocacy directorate, the Head of Patient Advocacy will contribute to the delivery of the business's strategic, operational and departmental plans.

The role's core responsibilities include:

- Lead and manage the delivery of policy outputs supporting the delivery of Myeloma UK's strategic objectives, including diagnosis, access to treatment, living well with myeloma and strengthening patient voice in decision making
- Develop and lead on delivery of Myeloma UK's participation in submissions to UK Health Technology Assessments (HTAs) relevant to myeloma and related conditions
- Lead on external stakeholder engagement with key policy and clinical decision makers in cancer and myeloma treatment and care, including MHRA, NICE/SMC, NHS, DHSC, members of parliament and pharmaceutical industry leaders
- Lead Myeloma UK engagement on policy groups, coalitions and forums and attend and speak at relevant conferences and events
- Contribute to the development of and lead on implementation of Myeloma UK Patient Advocacy Strategies and Business Plan
- Lead and develop the Patient Advocacy team

- Plan and manage the Patient Advocacy budget, including ensuring adherence to operational plan and expenditure forecast

- Develop strong collaborative and productive relationships with other Myeloma UK department heads and other colleagues across the organisation

- Promote and advance Myeloma UK's thought-leadership credentials in access to medicine meetings, roundtables, forums.

Key Deliverables

Patient Advocacy and Policy

- Design and deliver advocacy research projects in line with strategic objectives, including commissioning and managing research and policy work by external agencies

- Develop and deliver a programme of evidence-based policy position papers in line with strategic objectives, working closely with colleagues in Lived Experience and Clinical Practice Services and Health Services Research

- Provide briefings for the Director of Research and Advocacy, Executive Leadership Team (ELT), CEO and Trustees on policy landscape and initiatives

- Lead on engagement with and responses to relevant Government, NHS, industry and HTA policy consultations, including UK Life Sciences and national cancer strategies

- Working with the Head of Campaigns, engage with elected members in the UK and devolved Governments and legislatures

- Develop effective working partnerships with policy and advocacy functions in other third sector organisations

- Represent Myeloma UK on relevant coalitions and working groups

HTAs, IPTRs and individual requests from patients/clinicians

- Oversee 100% participation to myeloma HTAs and ensure that submissions are of the highest quality and meet regulatory requirements including participating in NICE and SMC Committee Meetings

- Support the Patient Advocacy Team in provision of best quality advice to individual clinicians and patients on treatment policy and treatment availability

Communications

- Work with the Communications and Brand Team to promote Myeloma UK advocacy and policy work and to develop and maintain our position as "thought leaders" in the cancer and UK Life Science health policy landscape

- This will include working with communications colleagues to develop content for web stories, press releases, social media content and, where appropriate, undertaking media interviews

Management and reporting

- Manage the departmental budget, reporting on performance and variances and work with the Director of Research and Advocacy to forecast, reforecast and conduct contingency planning

- Develop and collect KPI data and proactively report on performance and success to your team and the organisation regularly and as required and use the findings to make decisions to improve and develop the department

Line management

Line management responsibilities will include:

- Managing and motivating all direct reports

- Coaching, mentoring and supporting the team to enable them to perform to the highest standard to contribute towards achievement of organisational goals and objectives

- Effectively managing team performance, including carrying out annual appraisals and quarterly performance reviews within organisational timescales

- Identifying appropriate learning and development opportunities for individual and team development

- Managing team absences and ensuring appropriate levels of cover at all times

General

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

General responsibilities include:

- 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
Qualifications & Experience	• Educated to degree level • Previous experience in an advocacy/policy role at a senior level • Experience of developing a strategic approach to policy and advocacy, building relationships with key stakeholders	• Experience of the cancer policy, treatment and access landscape
Knowledge	• Knowledge of the UK health policy landscape	• Knowledge of the cancer policy landscape • Knowledge of UK medicines approval processes
Skills	• Strong management and leadership skills • Excellent verbal and written communication skills, including ability to present to a broad variety of audiences	• Experience of representing an organisation at conferences, roundtables, alliance and coalition meetings, parliamentary receptions • Experience of partnership working including knowledge of the pharmaceutical and biotech industry
Personal qualities	• Self-motivated and ability to work as part of a team but also independently as appropriate • Ability to work under pressure and to strict deadlines across a range of projects • Flexibility and willingness to develop and expand the role • Credibility at a senior level • Flexibility to work out of hours and travel as required	

Terms and Conditions

Post	Head of Patient Advocacy (permanent, full-time)
Salary	£52,065 - £56,143
Probation period	Three months
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 organisation when required.
Holidays	Full-time holiday entitlement is 30 days per calendar year, plus 6 public holidays.
Pension scheme	Myeloma UK complies with its auto-enrolment obligations and offers a 7% pension contribution to all staff.
Premises	Myeloma UK is situated at 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG.