

Working with the Pharmaceutical Industry

Myeloma UK Policy

Background

Myeloma UK understands the importance of working in partnership with all stakeholders with an interest in myeloma, including the pharmaceutical industry, to achieve common goals. We acknowledge that both collaborative working and financial support from pharmaceutical companies is vital but at the same time we recognise the need for such partnerships to be transparent.

As a result, Myeloma UK has developed a policy document defining how we engage with the pharmaceutical industry. This will ensure we can withstand external scrutiny of our decisions and actions whilst at the same time allowing us freedom to work in a way which ultimately benefits myeloma patients and their families.

About the policy

This policy document defines how Myeloma UK works with pharmaceutical, diagnostic and medical device companies, including the funding we receive and the way in which we conduct our relationship with them. This is important to ensure that we:

- demonstrate our independence and impartiality
- are transparent, consistent and fair when working with industry
- maintain our integrity and reputation within the charity, cancer and health sectors
- remain true to our patient-centred approach, putting patients at the heart of everything we do to ensure best possible outcomes
- show our commitment to working collaboratively with pharmaceutical companies, alongside other stakeholders involved in myeloma, to improve patient outcomes
- remain accountable to our stakeholders and our Board of Directors

Rationale for working with industry

We work with pharmaceutical, diagnostic and medical device companies for a number of important reasons:

- to obtain important background information on treatments, diagnostic tests and medical devices
- that could benefit myeloma patients and improve the quality of treatment and care provided to them
- to enable us to produce factual, accurate, impartial and up-to-date information for our website and written publications on myeloma treatments, tests and procedures for patients and their families
- to provide opportunities to raise awareness of myeloma and to improve the quality of treatment and care in myeloma, including access to new medicines, tests and procedures

What type(s) of funding does Myeloma UK receive from companies?

Myeloma UK currently engages with around a dozen pharmaceutical, diagnostic and medical device companies, all of whom manufacture treatments, tests or equipment for use in myeloma. We also receive funding from the majority of these companies, either on an ad-hoc, annual or multiyear basis. The funding we receive comes in the form of the following:

- Project funding – to undertake a specific project of mutual interest and of benefit to the myeloma community
- Core funding – the company gives an unrestricted grant for Myeloma UK to support our programmes and services
- Donations in-kind – where the company offers services on a specific project

What rules do we apply to the funding we receive?

The total level of funding received from pharmaceutical companies on an annual basis does not exceed in excess of 10% of our total income, excluding research funding. The other 90% comprises voluntary donations from individuals and fundraising activities and we receive no statutory funding from Government.

All companies that Myeloma UK collaborates with must either be members of the Association of British Pharmaceutical Industry (ABPI) or adhere to the ABPI Code of Practice where relevant and applicable. The ABPI Code of Practice for the Pharmaceutical Industry 2019 sets out the obligations of pharmaceutical companies when working with patient organisations. Myeloma UK works to ensure that both parties in any agreement work to fulfil these obligations and adhere to its rules.

All funding is acknowledged in the Myeloma UK Annual Report, Annual Review and Financial Statement of Accounts.

What guidelines does Myeloma UK follow when working with the pharmaceutical industry?

- Myeloma UK collaborates with a variety of companies, giving no preference to any one company in particular
- We do not allow companies to influence our strategy, activities or information
- We will not promote, endorse or favour any particular product
- In order to ensure impartiality, funding from pharmaceutical, diagnostic and medical device companies will never exceed 10% (excluding research funding) of our total annual income.
- Myeloma UK retains the right to terminate any working relationship with a company who is seeking to coerce to conform to its agenda
- Myeloma UK will not disclose or share any confidential service user or supporter data with pharmaceutical companies or their agencies. Data Protection law including the General Data Protection Regulation, Regulation (EU) 2016/679 sets out the principles we must adhere to and other conditions which must be satisfied. Full details of our privacy policy can be found at myeloma.org.uk/privacy-policy/
- The way in which we conduct our relations with the pharmaceutical industry also applies to any public affairs or public relations agencies that pharmaceutical companies employ to act on their behalf

Use of the Myeloma UK name, logo and other publicity

- Our name must not be used by companies, their partners or agencies without prior consultation
- Written approval must be sought for any material or copy produced which refers to Myeloma UK
- Our logo must not be used without prior approval and must be used in compliance with the Myeloma UK brand guidelines
- Any press releases referring to Myeloma UK, or containing quotes from members of staff, must have prior agreement and approval
- Information and publications
- Myeloma UK retains full control over all its publications and printed materials even when they relate to a treatment provided by a particular company
- Where information relates to a type of treatment where there is more than one product available, Myeloma UK will include a full, factual and impartial description of each of these products in their literature and will make reference to available evidence and guidelines to support the use of these treatments
- Reference to both brand names and generic names will always be included in patient information

Surveys and market research

- From time to time, Myeloma UK will engage in collaborative patient surveys or focus groups, providing:
- They are sufficiently broad in focus
- Their objectives reflect our strategic aims and are of value to our organisation as well as the company
- Conform to good market research standards and are ethical
- Allow Myeloma UK to retain final editorial control, to 'pilot' the survey with our service-users prior to publication
- There is a commitment to publish the results in an objective (peer-reviewed) format

Policy and HTA submissions

Occasionally Myeloma UK will have shared policy goals with companies, such as the introduction of new treatments for myeloma. Advocacy activities, such as making patient interest submissions to

HTA bodies is not considered promotion of a product because these activities are intended to improve access to the treatment rather than recommend it be prescribed. However, in making HTA submissions we will always represent the patients' best interests and the content of these submissions remains completely free from influence by the manufacturing company.

We also work closely with other stakeholders such as clinicians and guideline groups and we will not endorse the adoption of products on the NHS where evidence and health economic information may be lacking or when they do not logically fit into the myeloma treatment pathway.

Myeloma UK will consider joint working on advocacy activities, but will not accept funding specifically or exclusively for these activities.

For policy and campaigning activities, we will work within the following framework:

- Independence, or perceived independence of our organisation, should not be compromised
- There must be complete transparency
- Information presented by Myeloma UK will objectively communicate the value that patients place on a specific treatment, from their own perspectives and where possible in their own words, garnered through surveys, anecdotal evidence and telephone interviews, compared to other standard treatments
- Myeloma UK may from time to time campaign for the availability of a treatment produced and promoted by a company from which we have received funding in the past or is currently receiving funding. In these cases the nature of this relationship will be fully declared, particularly with HTA submissions where this is a condition of submitting evidence

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Myeloma UK 22 Logie Mill, Beaverbank Business Park, Edinburgh EH7 4HG

 0131 557 3332

 myeloma.org.uk

 myelomauk@myeloma.org.uk