
Policy and practices in relationships with the healthcare industry

2021

1. Terms

- 1.1. "MS" is multiple sclerosis.
- 1.2. "People affected by MS" includes people living with the condition as well as family, caregivers and other people whose lives are affected by the disease.
- 1.3. "MSIF" is the MS International Federation, an international NGO registered with the Charity Commission in England and Wales (charity number 1105321).
- 1.4. "MS Organisations" refers to independent charities. These might be patient societies, organisations with the explicit purpose of supporting people affected by MS, or supporting research into MS.
- 1.5. "Member Organisation(s)" refers to members of MSIF.
- 1.6. The "healthcare industry" and "healthcare companies" refer to pharmaceutical manufacturers and partner companies, manufacturers and suppliers of medical devices and aids to daily living, dietary supplements, health management organisations, nursing/ homecare agencies and insurers.

2. Background

- 2.1. MSIF has formed a mutually beneficial relationship with the corporate sector over many years. The special feature that requires MSIF to have a clear policy on relationships with the healthcare industry is that, among our corporate supporters, they alone share an interest in the unique audience of MSIF and its Member Organisations. There is concern in many countries about the independence of organisations such as ours and it is important to us that we avoid possible perceptions of conflict of interest. Just as its Member Organisations wish to be seen to act only in the interests of people affected by MS, MSIF wishes to be seen to act in the interests of, and in concert with, its members; and also people affected by MS.
- 2.2. While MS organisations must act in the interests of people affected by MS, the health industries must satisfy their investors, their customers and the official regulators. It is therefore essential for us to be clear about where our interests overlap and where they diverge. For example, while it is in the interests of people affected by MS that drugs, devices or services are available and

accessible, increasing sales of the products or market share is a commercial objective.

2.3. MSIF will avoid exclusive support but will seek multi-company support wherever appropriate.

2.4. Support from the health industries for the work of MSIF is accepted in various forms. These include:

2.4.1. Financial support for MSIF programmes and projects.

2.4.2. Information about research programmes; including data arising from research such as trials, information for both technical and lay audiences about products.

2.4.3. Scientific and technical expertise.

2.5. Support must be seen to be proportionate and without influence on the shape or direction of MSIF programmes. MSIF will therefore avoid linking its programmes or income too closely to a company or sector of the health industries. Accordingly, we will accept support only if it is provided within acceptable conditions as described below; MSIF must retain control over program content and development.

2.6. In accepting support from the health industries MSIF recognises that it may be perceived by people affected by MS or the concerned public as promoting products or services. Equally, there could be a perception that funds provided to MSIF for its programmes contribute to the price of the relevant product or projected availability. We will therefore take all reasonable steps to ensure that there is no basis for such concerns. As a UK based charity, MSIF will also take into account the Code of Practice for the pharmaceutical industry 2016 of the Association of the British Pharmaceutical Industry (ABPI) (www.abpi.co.uk)

3. Respective roles and structures

3.1. MSIF wishes to have co-operative relationships with the members of the healthcare industry; the foundation for this is mutual respect for the aims and integrity of each party.

3.2. Activity that could give rise to actual or perceived conflict of interest is to be avoided; in particular, MSIF will always take rigorous measures to safeguard its independence and reputation.

- 3.3.** The companies and MSIF should familiarize themselves with each other's structures, relevant national regulations or law, and should respect the modes of operation at international region, national or local level.
- 3.4.** The industries are expected to avoid any activity or the creation of any organisation that could compete with MSIF or give rise to confusion about its identity.
- 3.5.** The basis of sound partnership is recognition of mutual rights and responsibilities. Written statements or agreements must be used to make this clear.

4. Use of name and logo of MSIF

- 4.1.** To avoid erroneous perceptions of endorsement, any linking of the name or logo of MSIF with companies, their products or services, must first be reviewed and approved by the MSIF CEO according to these criteria:
- 4.1.1.** The name(s) and logo(s) of MSIF are its exclusive property and may not be used without explicit prior written agreement.
 - 4.1.2.** If so required by MSIF, a company must say that MSIF has not endorsed its products or services.
 - 4.1.3.** Statements published in any form must be balanced, accurate and fair.
 - 4.1.4.** National or international regulations or restrictions on advertising to the public or patients will be observed and note will be taken of prevailing public opinion.
 - 4.1.5.** In statements that also refer to MSIF, a company cannot claim that the product is superior to or preferable to competitors' products unless the statement is true and MSIF agrees it is true.
 - 4.1.6.** Promotional material must clearly and conspicuously disclose if a company has made a donation in money or kind for the use of the MSIF name or logo.
 - 4.1.7.** Advertisements must make clear whether sales of the product will affect charitable support or contributions.

5. Credits and disclaimers

5.1. MSIF will always report donations from the health industries as part of its usual accounting and transparency arrangements and in line with UK regulations. Acknowledgement of financial or in-kind support by companies will be made for all supported programs. . References will be to company names rather than specific products.

5.2. Credits in print or electronic media will be agreed with companies before publication or production. MSIF will exercise the final decision about the relative prominence, size or dominance of its own or company logos or credits.

5.3. The following are typical credits; the exact wording will be at the discretion of the MSIF CEO:

For MSIF-originated material:

'Publication of this (booklet, etc.) was made possible by a grant from XYZ Company.' (A company logo may be included at MSIF's discretion).

For MSIF-produced audio-visual material:

'Supported by a grant from the XYZ Company.' (A company logo may be included at MSIF's discretion).

For display material at events:

'We thank X company for its support.'

5.4. Where MSIF is involved in the preparation of material about MS for a company, its assistance can be publicly acknowledged; however, the content should not include product identification. A typical acknowledgement is as follows:

'Prepared with technical assistance from MSIF.'

5.5. In addition to the credit, a disclaimer may also be used on publications and other materials. A disclaimer will normally follow a credit statement and could be as follows:

'Acceptance of financial support from a company does not constitute endorsement by MSIF of any product or service of a Company.'

6. Information exchange

6.1. MSIF maintains the right to present information relating to a company's products or activities as it feels appropriate and will rely on documented evidence and the advice of knowledgeable practitioners in presenting such

information. MSIF will retain control of the presentation of such information; it will not act as a conduit for advertising, explicit or implicit.

- 6.2.** MSIF will acknowledge support of companies as set out in section 5.
- 6.3.** MSIF welcomes provision of evidence-based information about drugs, devices or services and the trials in which they have been tested. It recognises that the industries will wish to present their products and services to the market in the best light; however MSIF will always seek independent verification of data.
- 6.4.** MSIF wishes to receive advance information from the companies on new products or licences.
- 6.5.** MSIF may produce information about specific products, but will refer to other products of a similar class when appropriate.
- 6.6.** MSIF may choose to recommend the provision of a particular product, but will normally not endorse it beyond reference to the published evidence on which a marketing authorisation or the manufacturer's claims of efficacy are based.
- 6.7.** MSIF cannot accept requests to be quoted in any industry press release or sit on any panel related to a specific product or individual company. However, appropriate and accredited citations from its publications are welcomed. Quotations for use by several organisations/companies may be provided for non-company or non-product specific releases.
- 6.8.** MSIF is interested to receive advance data about products and trials from manufacturers, where confidentiality does not give rise to a conflict of interests.
- 6.9.** In published material in any form, MSIF will always draw attention to known adverse effects, including interactions, safety and side effects.
- 6.10.** MSIF will not open its mailing lists to the health industries, but may under certain circumstances agree to circulate invitations to those on its lists to make independent contact.
- 6.11.** Information provided by MSIF to a company must be credited in publications and its use must be agreed with MSIF before publication. Such information cannot be used to claim or imply endorsement by MSIF.

7. Public relations, promotion, advocacy and lobbying

- 7.1.** MSIF will always make advocacy decisions based on the interests of people affected by MS and its members, without consideration if they advance or conflict with the interests of members of the healthcare industry.
- 7.2.** MSIF & Member Organisations may seek to contribute to international regulation of medical, pharmaceutical and biotech research, and of healthcare products.
- 7.3.** MSIF may consider joining with healthcare companies in public activities relating to the availability of products and services.
- 7.4.** If appropriate MSIF may consider linking up with the healthcare industry in political lobbying or advocacy.
- 7.5.** MSIF is prepared to consider participating in advertising and related activities, within the limits set by current UK and international legislation.
- 7.6.** Where healthcare companies initiate advocacy initiatives, MS Organisations shall generally consider individual elements of these and take their own action as they see fit, independently from the company. Generally, they will not alone or as a group sign up to such initiatives from healthcare companies.

8. Educational events

- 8.1.** MSIF is prepared to consider participating with the healthcare industry in educational activities for its Member Organisations, health professions and people affected by MS; including conferences, regional seminars, skill sharing, or symposiums.
- 8.2.** MSIF staff and advisers are ultimately responsible for the identification of needs, determination of objectives, content, speakers, methods and materials. Speakers will be requested whenever possible to use generic names of products rather than trade names during events.
- 8.3.** Donations may be accepted in support of MSIF educational events that are developed for Member Organisations, health care professionals, volunteers and people affected by MS, subject to the following conditions:
 - 8.3.1.** Financial support will be accepted as grants. It is acceptable for funding to be specified for elements of a programme, e.g. speaker costs, travel, refreshments or materials.
 - 8.3.2.** Speakers will be informed in advance of the requirement for a balanced presentation about the range of therapeutic products or services. They

are expected to provide accurate and unbiased information and to answer questions objectively.

8.3.3. Sales representatives may not present educational material.

8.3.4. The nature of industry support for the program and/or speakers will be made public at meetings. Speakers should also disclose to the audience any working financial relationships they may have with companies.

8.4. Educational materials such as booklets, brochures, leaflets, newsletters, posters, or videos may be written and produced with the assistance of unconditional grants from the healthcare industry. Responsibility for content, selection of writers, illustrators or other contributors rests with MSIF.

9. Industry displays and materials

9.1. International or national legal or regulatory restrictions on promotion of drugs, devices and other products must be observed by the companies and MSIF.

9.2. MSIF will not agree to direct promotion or sale of drugs or devices requiring a physician's prescription at events taking place in, or associated with, its name. General information about such product ranges and company information may however be made available.

10. Research

10.1. MSIF initiated research projects supported by the health industries must have formal approval of the MSIF Board, be ethically, socially and scientifically acceptable according to international norms and those of the country in which they take place. Participation of MSIF in industry-initiated research projects must meet the same criteria.

10.2. MSIF prefers joint arrangements with more than one company for funding or otherwise supporting research projects.

10.3. Where any commercially viable property results or may result from jointly supported research, MSIF requires the company/companies to agree to profit sharing arrangements.

10.4. MSIF & Member Organisations may consider potential commercial activities in relation to healthcare companies, such as marketing of intellectual property (IP) or promotion of commercial translation of research.

10.5. MSIF & Member Organisations aim to increase their international cooperation in relation to research and value the contributions that healthcare companies can make to these efforts. They will aim to be proactive in commenting on the priorities of healthcare companies and to represent the opinions and perspectives of people with MS to them.

10.6. There are circumstances where a collaboration develops between MSIF or a Member Organisation and a healthcare company relating to translation of research into treatments. In such cases some of the provisions of this paper, such as articles 12.3.1, 12.3.2 and 12.3.4 may not apply. However, the principles contained in sections 6 and 12 will always apply.

11. Confidentiality

11.1. It is the responsibility of MSIF to assist in maintaining, with its Member Organisations, the privacy of people affected by multiple sclerosis and their professional and volunteer caregivers.

11.2. MSIF staff and volunteers do not provide names of people affected by MS to the members of the healthcare industry.

11.3. Mailing lists are not provided to, or shared with, external organisations.

11.4. Evaluation of events by individual participants will be anonymous except where the participant chooses otherwise.

11.5. Participants attending events organised by or in conjunction with MSIF may choose to sign a company mailing list, but it will be made clear that this is not required by MSIF.

12. Guiding principles

12.1. Guiding principles for relations with healthcare companies are:

12.1.1. Benefits to, and interests of people affected by MS;

12.1.2. Giving voice to the hopes and concerns of people affected by MS, including the issues of cost, access, efficacy and safety of existing and new treatments;

12.1.3. Independence and being seen to be so;

12.1.4. Safeguarding against undue influence by the healthcare companies;

12.1.5. Transparency;

12.1.6. Clarity of the aims of any relationship;

12.1.7. Equal treatment of healthcare companies;

12.2. The overriding practice in the relationships will be for MSIF and Member Organisations to take the initiative by guiding and setting the agenda. Where appropriate, they will actively invite representatives from healthcare companies to contribute to relevant seminars and meetings where their expertise could contribute.

12.3. Healthcare companies will invite MSIF & Member Organisations to participate in meetings on specific subjects. If judged useful, and in light of the section 6, MSIF and Member Organisations can choose to attend such meetings on the basis that they will:

12.3.1. wherever possible, identify themselves as attending with observer status only. As such they could make comments, but not be identified as sharing responsibility for the outcome of such meetings. Presence at such meetings should not be used to imply agreement with the outcome;

12.3.2. publicly disclose their attendance as observers in such meetings and not accept restrictions on their ability to do so;

12.3.3. wherever possible, avoid reimbursement for travel or lodging;

12.3.4. not sign confidentiality agreements with healthcare companies. If confidentiality agreements are required, use MSIF's pro-forma;

12.3.5. not accept consultancy agreements.

13. Membership

Adherence to the Guiding principles will form part of the criteria for full MSIF membership.