

# Relationship between the European Multiple Sclerosis Platform (EMSP) and the pharmaceutical industry



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## A Code of Conduct (Approved August 2012)

This Code reflects provisions within the European Patients' Forum Funding Framework and Code of Ethics, and the EFPIA Code for working with Patients' Groups

### A: Background

A1. The European Multiple Sclerosis Platform (henceforth 'EMSP') is an independent not for profit organisation that wishes to ensure a positive, transparent and collaborative relationship with a number of stakeholders including the pharmaceutical industry and its associated businesses (referred to as the 'pharmaceutical industry' in this document) whether these operate at national, European or global level.

EMSP recognises the considerable public interest in the activities of the industry and in the relationships that it develops with voluntary organisations. It also acknowledges that relations with the pharmaceutical industry are in many respects similar to those between the MS Societies and any other sectors of business and industry. However, the industry has a unique interest in the same audience as the MS Societies and therefore has a special standing.

A2. This Code of Conduct is produced by the EMSP as a guide to representatives of the pharmaceutical industry to establish a clear understanding of roles each can play, to ensure independence and transparency, for the avoidance of doubt and for public interest and awareness. This Code will be reviewed regularly and updated as relationships with the pharmaceutical industry and public and legal expectations change.

A3. There are at present no laws at European level regulating relations between the voluntary health organisations and the pharmaceutical industry. However, the relationship between the industry and the general public is strongly regulated at EU and national level. The most directly relevant regulation is European Directive 92/28/EEC on the advertising of medicinal products (annex). Additional regulations and codes in different countries have implications for relations between MS Societies and the industry. These are interpreted in different ways according to the national environment and traditions. The EMSP will work within the more strict codes and regulations. This code draws on the EFPIA Code of Practice for working with patient groups, and the EPF's funding framework.

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## B: The standards

### 1. Respective Roles and Structures

1.1 It is recognised that there are common interests between the EMSP and the pharmaceutical industry, e.g. the wellbeing of people with MS, take-up of effective medicines, development of new and more effective treatments, rigorous clinical trials of medicines, understanding of MS and the need for treatment, education of patients, physicians and health workers. Relationship Between EMSP and the Pharmaceutical Industry

1.2 Separate interests are also recognised, i.e. that the EMSP exists for the public good, to advocate on behalf of people with MS and does not produce private profit or other benefits, while the industry must satisfy its investors and shareholders and is obliged to make profits to exist and to fund future medicine development.

1.3 The EMSP wishes to have co-operative relationships with the industry and individual companies; the foundation for this is mutual respect for the aims and integrity of each party. Activity that could give rise to conflicts of interest is to be avoided; in particular, the EMSP will always take rigorous measures to safeguard its independence and reputation.

1.4 The companies and the EMSP should familiarise themselves with each other's structures, relevant national regulations or law, and should respect the modes of operation and representativeness at European, national or local level. The industry is expected to avoid any activity or the creation of any organisation that could compete with the EMSP or give rise to confusion about its identity.

1.5 The basis of sound partnership is recognition of mutual rights and responsibilities, principles of independence and transparency and written statements are required to make this clear and public.

### 2. Guidelines for non-funding relationships

2.1 EMSP values its relationship with industry particularly with regards to sharing of expertise, skills and knowledge in relation to medical research in MS. EMSP will aim to be proactive in commenting on priorities for industry and to represent the opinions and views of persons with MS.

2.2 All industry meetings/events attended by EMSP must have a legitimate purpose and be compliant with this code of practice.

2.3 The status of the EMSP attendee must be made clear in advance and at the meeting/event e.g. Information giving/exchange; consultation; sharing; observation.

2.4 For meetings/events organised by industry attended by EMSP, there must be a written agenda circulated in advance of the meeting.

2.5 Written minutes/records of meetings/events must be submitted to the EMSP representative for their approval.

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2.6 Participation by EMSP on industry working groups & advisory groups must be subject to written clarification/criteria and must be transparent. E.g. Observer; attendance for information giving/sharing only or consultation purposes or other code appropriate purposes.

2.7 Attendance at a meeting by an EMSP representative should not be taken as approval/endorsement for any decisions taken at the meeting or for any documents/policies emanating from the meeting. Any approval/endorsement has to be subject to EMSP code and written agreement.

2.8 If there is lack of clarity or doubt by an EMSP representative while at a meeting, the EMSP representative should stop the discussion until the appropriateness of the topic can be confirmed.

2.9 When an EMSP representative is present at an industry led scientific meeting, the EMSP representative should identify themselves as attending as an observer only and not be identified as contributing or sharing responsibility for the outcome of such meetings.

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## 3. Information Exchange

3.1 The EMSP welcomes provision of information about medicine and medicine trials. It recognises that the industry must present its products to the market in the best light and that the EMSP will seek independent verification of data.

3.2 The EMSP wishes to receive advance information from companies on new products or licences. It is expected that additional demands will not be placed on the EMSP information services without adequate warning.

3.3 The EMSP may produce information or publish existing material in the public domain, but will always also refer to other medicines of a similar class. For the publication of information regarding medicines on the EMSP website, one of these options will be used:

- 3.3.1. EMSP copies text already available on the UK MS Society Website (which has been screened by UK colleagues in order to avoid any promotional content. UK is used as editor because of English being EMSP's language.).
- 3.3.2. Medicines will be mentioned on our Website (by substance not by brand name) and then links will be made to information on the European Medicines Agency Website.
- 3.3.3. Where EMA information is not available we will make a link to the Website of the National Competent Authority that has approved this medicine.

3.4 The EMSP will not recommend the provision of a particular medicine, and will not refer to a medicine beyond reference to the published data on which a marketing authorisation is based.

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3.5 The EMSP welcomes confidential data about medicines and trials and will accordingly respect embargoes on public disclosure.

3.6 Information on clinical trials on the EMSP website is limited to a short piece of information on the start, the current status or the end of a clinical trial, followed by the recommendation to the readers to contact their National MS Societies for more information.

3.7 In published material in any form, the EMSP will always draw attention to known medicine interactions and adverse effects.

3.8 The EMSP will not open its lists of members, patients or supporters to any commercial organisations beyond what is in the public domain.

3.9 Information or data provided by the EMSP to a company must be credited in publications and its use must be agreed with the EMSP before publication. Such information or data must not be used to imply endorsement of a product or company by the EMSP.

3.10 A grant or payment for the use of such information or data will not be required or accepted by EMSP.

3.11 The EMSP is prepared to accept sponsorship from a company for its publications or other information products or events (see section 5). Relationship Between EMSP and the Pharmaceutical Industry

### **4. Public Relations, Promotions and Lobbying**

4.1 The EMSP will not join with a company in public relations activities relating to the availability of individual medicines or classes of medicine.

4.2 When industry initiates advocacy initiatives EMSP will normally not participate in these but may consider individual elements of them and take its own action as EMSP sees fit independently of the company. Generally EMSP will not sign up to such initiatives. The EMSP is always prepared to consider participating with the industry in educational activities for its members/patients and health professionals as long as the terms of reference are fully in line with EMSP's and EFPIA's Codes of Conduct.

4.3 The EMSP will not participate in industry or company advertising and related activities.

4.4 All information provided to the EMSP's publications or events must be within the terms or current national/international law and conventions. The EMSP will not attempt to use its status as "International Not For Profit Organisation" to circumvent these.

4.5 When an umbrella body or similar multiple industry representative body develops an advocacy initiative, not identified with any one pharma product or company, EMSP may consider participating in such an initiative with the approval of the ExCom.

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## 5. Research

5.1 The EMSP encourages the industry to publish as much research data and conclusions as possible and only to keep confidential the minimum of commercially sensitive data.

5.2 The EMSP will not invite its members/patients to enrol for clinical trials or other approved research but will make available information on current and upcoming calls. This is in line with the patient community's response to the Clinical Trial Directive Impact Assessment. The EMSP may ask its member societies to draw the attention of Persons with MS to requests but not provide direct access to PwMS or share their mailing lists.

5.3 The EMSP believes that the choice of medicines should be made freely between doctor and patient, and should not be influenced by commercial considerations.

5.4 Subject to independent advice and depending on the individual case and purpose, the EMSP will consider providing anonymous statistical or epidemiological data about its members or patients and their care givers.

## 6. Pharmaceutical Company Displays and Materials

6.1 EU and national legislation and codes of practice, prohibiting the advertising of prescription-only medicines to the general public, apply. It is illegal in member society countries for pharmaceutical companies to advertise prescription medicines directly to consumers. Therefore pharmaceutical companies cannot set up a display booth to promote the company's prescription medicines at an EMSP or MS Society organised programme or event. The company can act as a sponsor and be offered the opportunity to be acknowledged for this support in meeting programmes, on signs and through oral acknowledgement. Only the name of the company can be used, not the product.

6.2 It is acceptable to have available at a workshop or educational session, company brochures or handouts providing the information is restricted to describing aspects of the company, not its products Relationship Between EMSP and the Pharmaceutical Industry Page 5 information or product support telephone lines and web sites. Such materials can be made available to individuals who wish to have them (for example, placed on a table in the room), but should not be distributed to each participant. It is not acceptable for a company to attempt to sell their medicine product at a workshop or educational session.

6.3 Therapeutic devices and some other non-prescription health care products may be displayed to the general public at EMSP events as long as these devices do not claim to treat or cure a disease or condition. Therefore, display booths of such products as wheelchairs, walkers and other equipment can be set up at EMSP programmes or events and can be acknowledged in meeting programmes, on signs and through oral acknowledgement.

6.4 The overriding practice in the relationship between EMSP and industry is that EMSP guides and sets the agenda/programme. If EMSP invites an industry representative to present or speak to its audience, then it should be made clear to the speaker what is not allowed within the code of practice and what is appropriate for the audience.

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## 7. Code for Funding relationships

7.1 The EMSP welcomes unrestricted grants from industry and will always report these as part of its usual accounting and transparency policy.

7.2 When pharmaceutical companies provide financial support, significant indirect support and/or significant non-financial support to EMSP they must have in place a written agreement. This must state the amount of funding and also the purpose (e.g. unrestricted grant, specific meeting or publication, etc.). It must also include a description of significant indirect support (e.g. the donation of public relations agency's time and the nature of its involvement) and significant non-financial support. Each pharmaceutical company should have an approval process in place for these agreements

7.3 Wherever possible, the EMSP will seek to have funding from more than one company.

7.4 Unrestricted donations are welcomed by the EMSP in respect of its annual work programme, but will not be accepted as an inducement to influence or change its positions on issues, plans or priorities.

7.5 Private donations to individual officers or members of the EMSP, whether paid staff or volunteers, are not acceptable.

7.6 When the EMSP accepts a donation in support of any specific activity it retains control of the content at all times.

7.7 EMSP welcome invitations to industry events, providing reasonable travel and subsistence costs can be covered, and where appropriate, an honorarium to EMSP to compensate for time invested by staff or elected representatives

7.8 The EMSP will ensure that up to date information on funding sources and amounts will be made available in its annual report and published on its website Relationship Between EMSP and the Pharmaceutical Industry

## 8. Acknowledgements and Disclaimers

8.1 The EMSP welcomes donations from the pharmaceutical industry and will always report these as part of its usual accounting and transparency arrangements. Acknowledgement of financial support by sponsoring companies will be made for all supported programmes and research; however, references will not be made to specific products, only to the corporate name. We ensure that we are able to demonstrate that any funding we receive is unconditional and we seek to identify funds from a variety of sources in order to maintain independence.

8.2 The following are examples of acceptable acknowledgements: For EMSP produced audio-visual material:

“Produced by the EMSP, supported by an unrestricted educational grant From XYZ company. “(Company logo may be used).

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8.3 If the EMSP is involved in the preparation of material about MS for a company, the EMSP assistance can be publicly acknowledged, e.g. by the sentence: “Prepared with technical assistance from the EMSP.” However, the content should not include product identification.

8.4 In addition to the acknowledgement, a disclaimer is also required on publications and other materials. An acceptable disclaimer is as follows:

“Acceptance of this unrestricted educational grant of XYZ Company does not constitute endorsement by the EMSP of any product of XYZ Company. The EMSP does not approve, endorse or recommend any specific product or therapy but provides information to assist individuals in making their own decisions.”

### 9. Satellite Events proposed and sponsored by the Industry

“Satellite Events” proposed and sponsored by the industry in conjunction to an EMSP event should:

- Have a link to the main subject of the EMSP event
- Be open to anyone who wants to participate
- Only use speakers who are known as being independent from the sponsoring company
- Not focus on one specific medicine of the sponsoring company
- Be administered by EMSP, respecting the protection of personal data (e.g. invitation template from the sponsoring company to be mailed together with EMSP cover letter; feedback of a list of participants (with numbers of delegates and participating countries, but no names) to sponsor by EMSP; budget to be administered by EMSP

EMSP will seek to spread such funding opportunities amongst interested companies.