ms international federation

EUROPEAN MULTIPLE SCLEROSIS PLATFORM

Meeting report & actions

Pharmaceutical industry & patient organisation Round Table

Context

MS patient organisations all over the world rely on financial, and sometimes non-financial, support from the pharmaceutical industry to enable delivery of programmes for people affected by the disease. The relationship between companies and patient organisations is an important one because both are important stakeholders in the MS space. There are several areas of obvious crossover (improving health of people with MS or access to treatment, for example) but both also have interests not best served by the other (individual company profit vs absolute focus on patient wellbeing irrespective of profit, for example).

Whilst the relationship between patient organisations and companies clearly has many benefits, it also brings a number of challenges and it is vital that these are addressed. In February 2019 the European MS Platform (EMSP) organised a roundtable session to begin raising these issues, which was followed up by a teleconference in the early summer. The MS International Federation (MSIF) has also been raising this with individual companies and at its board meeting in April 2019 the Board called for MSIF to formalise this work and to partner with EMSP. The industry and patient organisation roundtable at ECTRIMS 2019 was the first iteration. It was chaired by Elisabeth Kasilingham, General Manager of EMSP, and Peer Baneke, CEO of MSIF, and facilitated (pro bono) by Graham Piercy of Anagram Communications.

Roundtable – September 2019

Participating patient organisations	Participating companies
MS International Federation	Almirall
European MS Platform	Biogen
DMSG (Germany)	Celgene
Esclerosis Múltiple Uruguay	Genentech
Ligue Française contre la Sclérose en Plaques	Janssen
MS Society of Canada	Med-Day
MS Society of Israel	Merck (EMD Serono)
MS Society of Poland	Mylan
National Multiple Sclerosis Society (USA)	Novartis
Neuroforbundet (Sweden)	Roche
SPEM (Portugal)	Sanofi Genzyme
UK MS Society	
Facilitator: Graham Piercy	

Below is a summary of the presentations and discussion. The conclusions and next steps are captured in the subsequent section.

Introduction

The meeting and goals were outlined in an introduction from Elisabeth Kasilingham of EMSP. We have many common interests and collaboration success stories, such as new and effective drugs, the International Progressive MS Alliance, and the new Patient Reported Outcomes project launched this week, PROMS.

These are celebrated by us all, but we also have some challenges where our different priorities or approaches lead to misunderstanding or conflicting demands. The first step is to acknowledge problems. This meeting is to address these with an open mind, and to make progress through transparent discussion and agreed outcomes.

Shared Values

Interestingly, the suggestions from the floor and subsequent discussion focused more on shared *goals* than shared *values*. This may reflect that there are more shared practical interests than shared values, or it may be simply that they are easier to vocalise. The shared values included:

- Improved patient outcomes.
- Patient centricity.
- A world without MS, a cure.
- Living the best life you can through MS journey – improving quality of life.
- Awareness raising to enable people with MS to participate in society
- Providing support and resources to people with MS:
    - Education.
    - Awareness.
    - To help them advocate for themselves.
    - Empowering people with MS.
- Access to medicines, drugs and treatment.
- Honesty and integrity.

The discussion about where our values or goals diverge was also interesting. The obvious difference was that every company has a profit motive, which has some significant impacts. These include:

- Company decisions about investment in research are taken with a long-term perspective. However;
- Decisions about funding patient support/advocacy programmes are made with short term (often one year) goals;
    - These decisions can also be focused on company timescales/goals rather than the goals of people with MS.
    - There is a need to differentiate themselves from competitors which can lead to a tendency to go it alone rather than undertake common activities with other companies.

- For patient organisations the primary goal is improving quality of life and sustainability of treatment, care, services and support. As a result longer-term thinking and planning are necessary, as is collaboration.
- Generating evidence and research supports better outcomes. The drivers for research differ from companies to MS societies. The intent is always a better understanding of MS but industry changes from scientific proof to whether the molecule can be commercialised.
- Even within the MS community there is difference and ‘competition’. We do see some competition between patient organisations, especially at a national level.

Challenges of working together – Industry perspective

Vanessa Pott of Merck (EMD Serono) presented an industry perspective on the challenges of working with patient organisations. There was a recognition at the opening that most/all of the people in the room are those who understand the importance of a healthy relationship. The key headlines were:

- Trust issues and power balance.
    - In terms of resources it is a David and Goliath situation but if industry wants strategic partnerships then we need to talk as equals.
    - There is scepticism in patient organisations and in the general public about motivations and intent, especially when establishing new relationships or collaborations.
    - It is a highly emotive topic.
- Fragmented landscape in patient community.
    - Not just geographically. There are different patient organisations in each country, but also within countries. Sometimes competition, personal and political issues, makes it hard to work with patient orgs – e.g. a plan to illuminate public buildings to mark World MS Day became a nightmare because the patient groups couldn’t agree on which buildings to illuminate!
    - Changing representation of the patient voice. Traditional patient orgs vs emerging actors which industry need to evaluate how to work with them e.g. individual influencers, trained patients gone through EUPATI, digital networks that can become quasi organisational – all can be a strong voice. Need to take these actors into account and how do we know who is representing collective rather than subjective perspective. How to engage with emerging network without destabilising relationship with established group.
- Lack of expertise, resources and time.
    - Specifically at a technical level, such as ability to contribute to scientific, legal or technical work. This can cause an internal issue, explaining to colleagues why patient organisations can’t get involved in a new programme.
- Funding and independence of the patient orgs
    - There is a tension here. They want to fund projects but companies don’t want to work with patient orgs as puppets of industry.
- The nature of pharmaceutical companies.

  - Companies are big and the further you get away from the centre the harder it is to maintain uniform behaviour and practices. Especially with differences in ownership, leadership, laws and culture.
  - Some people in companies simply don't understand the boundaries. Some see patient organisations as extension of the marketing department, while at the other extreme, some national/regional teams don't even talk to patient orgs!
  - There is a need to drive culture change throughout the industry. Patient organisations need to be known and understood by every colleague.

Challenges of working together – Patient organisation perspective
Presented by Peer Baneke of MSIF, this was an insight into issues that patient organisations around the world raise with MSIF and EMSP but often feel unable to address themselves.

- Companies dominating the airwaves.
  - Using World MS Day as an example, it is fantastic that companies want to celebrate World MS Day but due to the difference is budget and media reach companies can drown out the voices of people with MS and patient organisations who are the primary subject and audience of the Day itself.
  - Also, sometimes the use of the logo itself can make it look as if World MS Day is a company initiative, which is why we developed and shared the guidelines.
  - But it is much easier for an established organisation like MSIF to voice concerns over this kind of thing than smaller organisations who may not have as much agency or strong relationships with the companies in their country.
- Unbranded[1] or micro-branded[2] communications.
  - Companies will sometimes launch websites, apps, events or other platforms (referred to as platforms from here on) for engaging the patient community but difficult to see who is running the show.
  - It is very unusual for a platform with *absolutely no details* of ownership, but most patient organisations have experienced one or more micro-branded platforms. This includes where you have to search for ownership details in very small writing at the very bottom of a page, in deep links or terms and conditions.
  - Be bold and open - Who is running what? Clearly stated on the top of the page.
  - If company initiatives are not set up explicitly it is difficult to not to be suspicious of the intent.
- Power, independence and influence: Three subcategories:
  1. Behavioural particularly smaller orgs being asked to do what the company wants, (internal guidelines, training programmes might help),

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[1] It became clear in the discussion that the use of the term 'branding' or 'branded' meant something different to the two audiences in the room. MSIF and many of the patient organisations used this term to mean 'not displaying the company logo', whereas companies understood it as referring to 'an unbranded treatment'. It was agreed to avoid this term in future to avoid confusion.

[2] This term was coined by the presenter, Peer Baneke, to refer to the company logo or details of ownership/origin being small, hidden or otherwise unclear.

2. Financial support is sometimes used to influence patient orgs to get on board with a company initiative. For example;
    - When a company says they will only fund a patient organisation if they undertake a particular project there is a significant risk that vulnerable patient organisations abandon their independence because they need the money. Only asking patient organisations to do your projects should not happen.
    - Funding patient organisations to advocate to government on a particular issue or treatment totally undermines the independence of the organisation, which is devastating to their reputation.
3. Where money is used to stop or change a course of action the patient organisation is embarking on, such as changing a policy or advocacy position.
    - Pharma should not influence policies and strategies of patient organisations. Respect their values and independence.
    - In most cases it is difficult to judge if this is truly the intention of the company.
    - For example, when funding gets significantly reduced around same time as the displeasure with the patient organisation's approach is communicated.

Challenges of working together – Discussion

This discussion took up the majority of the time. It addressed both perspectives and was quite wide-ranging. It is therefore too difficult to capture the discussion verbatim, so this report tries to capture the essential points that were made. There was broad agreement that the content of the presentations was fair, so this will not repeat points that mainly supported the points made. The consensus is captured in "Conclusion & next steps".

What was missing from the presentations?

- Time element – short and long term perspective on goals/impacts.
- The operating environments for some patient organisations are very difficult, with a huge diversity of economic, cultural, and political contexts.
- Relations with pharma companies have changed, the balance has changed.
    - 10 years ago support was primarily for MS organisation projects. Now there is more of a push to make MS organisations support company initiatives, or to primarily fund MS organisation programmes that match company priorities.
    - A challenge for industry is that transfers of money/value have become more complex through stricter regulation. '*How* we fund' has changed so we need to understand better how each other works.
    - Companies used to be able to fund wider work, but the changes are for good reason; for example, to protect independence by not providing core funding.
    - Patient organisations applaud the intent of regulations that prevent core funding, but how some of these 'protective' rules are interpreted and the real-life impacts on their work make them do more harm than good, because to undertake the projects parts of the overheads and part of the time of long term staffing need to be funded.

- When a patient organisation goes to a company with a project that they know will match the company agenda they are already influenced.

How do we improve?

- Long-term vs short term discussion:
    - 12 month funding cycles make it impossible to make long term plans. This is a real challenge and not a sustainable way to work together.
    - There are consequences if industry approaches relationships with patient organisations with short-term goals in mind and doesn't support the long-term capacity of MS organisations.

CASE STUDY: An example of the damage of short-term thinking

Raised in the meeting by a patient organisation in Europe.

An external marketing company was hired by a pharmaceutical company to develop a patient education campaign that supports the company's priorities. The marketing company knew nothing about MS and did not make an effort to listen to the patient perspective, but throws money at the campaign.

The effect of this campaign was to set MS awareness in the country back 10 years, because of the language the marketing company chose to use. As a secondary result the small, underfunded patient organisation is distracted from its main purpose but now feels it needs to get involved with future company-sponsored activities to prevent this happening again.

- Micro-branding discussion:
    - 'Transparency' isn't enough. A platform is *technically* transparent if it has ownership details buried in deep links. It needs to be immediately obvious and explicit.
    - Companies develop specific content to fill a gap, and in large companies there are various teams who could be responsible for this which are not at this meeting, e.g. marketing or digital.
    - Conversely, patient organisations sometimes contribute to the thinking on activities/content but don't want to be acknowledged as they don't want to endorse the content. Transparency needs to go both ways.
    - Could a possible solution be to make clear guidance on size/placement of logos? Go above and beyond the compliance code. Develop best practice and standards.
    - Perhaps to develop similar guidelines for industry as those for World MS Day?
    - Don't forget to roll this out to country level and affiliates, otherwise standards won't change anything in real practice. Needs to be in the learning plans of staff.
    - Also, if MS organisations become aware of these projects at local level, share them with compliance teams who have more resources and time to help address the problems.
- Trust discussion:
    - Can patient organisations ever trust the *intent* about educating, not promoting a brand?
    - Can industry trust patient organisations not to act counter to their interests?

  - It is possible for educational campaigns to be formulated in a trustful way?
  - Haemophilia network created specific guidelines to establish trust. Can use this as an example. Other disease areas (cancer I think) have made a pledge. Create something overarching then get specific.
  - There is pressure on industry to change, but patient organisations also need to change and continually build trust.
- Behaviours and practices discussion:
  - It is a challenge having disease-specific codes of conduct. This discussion needs to go beyond the MS community.
  - Patient Focused Medicines Development (PFMD) could be leveraged so others can benefit.
  - Flag individual cases with global HQ. Different departments may appear short term in approach but the company is in it for the long term.
  - Need to start addressing a challenge small enough to work, not reinvent wheel, and get something out.
- Additional comments
  - Keep fragmented landscape on the agenda for future meetings.
  - ‘Power dynamics and independence’ is a long-term discussion to be tackled later.
  - The common desire to fund new projects is very damaging for patient organisations.
    - If a programme has been running for five, 10 or 20 years, it is usually because it is a good project.
    - These are the ones that need continued, sustainable support. Not just the shiny new things.
    - Even worse, when a company replicates a project being run by a patient organisation and moves funding from the patient organisation to their ‘own’ project.

Compliance (funding-related issues)

This section included four short presentations of real-life solutions to technical issues where the interpretation of Compliance guidelines in relation to funding has a negative effect on patient organisations. Each company had either solved the issue already, or were working on resolving it, so could speak to the actual issues involved. Presentations and the subsequent discussion included insight from patient advocacy and Compliance teams.

Novartis: Multi-year funding.

- Definition: More than 12 months and is across two fiscal years. This was a challenge for them but they saw the importance of this for their commitment and for the patient organisations.
- Led by patient advocacy and compliance together, with the finance team heavily involved.
- Compliance framework uses principle based questions to inform decisions. It is vital to ensure that there is a clear policy and no hidden agendas.
- Money needs to be ring-fenced in future years, to ensure that contracts are watertight.
- Contracts with patient organisations need to be different. They may have more specific targets or clear milestones along the way, to ensure that both parties know what they signing up to.

- When delays happen this needs to be addressed within the framework of the contract. There needs to be flexibility but it is vital any changes are communicated early and are not too frequent.

Novartis: Simplifying application forms and reports

- The company have also tried to simplify application forms and reporting, by making as many of the standard, essential bits of information as possible tick boxes.
- For example questions about transfers of value to health care professionals, that all the funding will be spent on the programme, travel will be economy etc.
- This removes some of the repetition that occurs in budgets and application forms.
- It also simplifies the reporting process for the patient organisation and The company.
- A template is available for other companies to consider.

Biogen: Paying for staff time/overheads

- Can't give 'core funding' grants due to trust and independence.
- Can support a project with clear objective and budget.
- The company will not *decide* what it is but need to *understand* what it is in order to review it.
- Biogen now recognise that projects don't happen in isolation. A patient organisation needs an office, power etc. In 2018 they amended their terms and allow for a portion of the grant to go towards operation cost – mindful to reality of how orgs operate.
- However, the questions are there for a reason, makes it easier to make decisions by review committee.
- Question from the floor – "Does the local company comply?" Answer: Aspiring to have same global grants process. Need to make sure what we put into our proposals is right as well.

Celgene: Avoiding budget line restrictions

- It is vital to communicate. Understanding the budget is very important to understand what you are funding, so grant requests and the supporting budgets need to be explicit about what they are funding.
- A layman with no experience of the organisation, condition or project should be able to know exactly what is being requested from the request and budget.
- When the grant and budget are detailed and in harmony the company can agree to fund a proportion of the whole project budget, not specific lines.
- There should be harmonisation in industry. Funding budget lines becomes like a wedding gift list. Companies will always select those budget lines that are easy for compliance but leave a big hole (such as overheads or other areas) for the patient organisations in order to implement the project.

Conclusions & Next steps

Companies/organisations/individuals inevitably have slightly different priorities, but there was a broad consensus and various ideas were proposed for how to take things forward. Below is a summary of the consensus on next steps.

Micro-branding

- Develop terms of engagement/terms of reference, co-create this and publish as a group. A truly collaborative project.
- Could be used by other diseases. How can we work together transparently, with trust?
- Working group to be established with people from industry and patient orgs.
- Decision to be taken about whether to invite EFPIA/IFPMA/PhRma.
- Should this be all encompassing or is that too wide a brief?

Next steps: MSIF & EMSP to set up a working group made up of industry and patient organisation representatives:

1. To address issues around transparency and deal with 'micro-branding' of websites, apps or other media;
2. Addressing the company overshadowing patient organisation events/activities (e.g. World MS Day).

Compliance & funding

The discussion was fairly short in this section due to time constraints, but it was clear there is huge interest in making funding and processes better. There was clear agreement that a working group to develop and harmonise as many best practice examples as possible was the outcome.

Next steps: MSIF & EMSP to set up a working group made up of industry and patient organisation representatives to improve policies, systems and processes for securing and managing funding.

Trust

- We need to bring in other colleagues and departments otherwise we are preaching to the choir
- How do we bridge agendas with influencers or digital communities, or do we need to accept we can't? How do we avoid duplication and waste of resources?
- If don't engage with them we don't solve the problem. We are in the digital age, have to go beyond this.
- It is not going to be easy to set up one framework, but we need ground rules to support the smaller MS organisations, to address their concerns.
- There need to be better mechanisms for preventing and reporting bad behaviours and practices. There was uncertainty between the ambition to resolve it across disease areas and another view that it needed to start small and 'achievable'.

Next steps: MSIF to convene a small working group

1. Mapping current initiatives addressing this issue.
2. Decide on direction & actions.