Myeloma Patients Europe (MPE)
Social Media Toolkit
Social Media Toolkit

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1 Overview

If you work within a patient advocacy group, offering quality information to patients, making your association better known or increasing the number of associates in order to be stronger may be among your priorities. This enables you to better advocate for access to treatment or early diagnosis but also involves a lot of work with probably few financial resources to do it.

However, we live in a world of digital communications. Some articles say that we check our mobile phones between 80 and 90 times a day, spending approximately five hours browsing the web and using apps. Social media is at the top of the list of the most used apps and most visited websites.

Maybe you are thinking that this has nothing to do with our objectives as advocates but if you look at this data carefully, you will probably realise that we have the attention of patients and stakeholders around five hours a day and all within reach of our computer.

Choosing the best way to share our content and the most suitable tool to reach our targets is one of the key things we need to do to obtain good results. However, using social media in an inappropriate way may involve some risks for your organisation because of misunderstanding or unsuitable answers.

This toolkit is a support resource for patient associations. Its purpose is to give guidance and information about social media management, in order to increase the visibility of your activities. Throughout these pages we will summarise some tips to get the greatest benefit from social networks reducing the risks that they may have for your organisation.
How social media can help you

A huge amount of information is shared every day on social media. People of different ages, with different levels of education and different social backgrounds, check their social media several times a day, and share their opinions and thoughts about different topics. All of them could be patients, carers or future advocates. This means that social media is a showcase for patient advocacy groups and is a good opportunity to raise awareness and give quality information about any disease.

The possibilities for sharing information are enormous. Pictures, written data, infographics, videos and even live videos are options you can use on social media. For any given objective, one network may be more suitable than others, but all of them can be used to share information and generate discussions amongst stakeholders.

These are some advantages of the use of social media within a patient association:

- **Reach people unknown.** Organisations have different ways of communication but most of them, such as emails, newsletters, and bulletins, are focused on the people that we already know. Social media can be seen by people who are not on your radar so give you the option to reach people you don't know.
• **Improving the dissemination of your activities and your opinions.** Although you have great activities and projects, if you don’t communicate them, it will be as if you don’t have them. It is important for associations that patients and stakeholders know all the projects they are developing. Big associations have communication departments that work to make their activities well known and deal with the media. Not all patients advocacy groups can afford to have staff specialising in communications but social media give them the chance to make public their activities for free whilst reaching out to a big number of people.

• **Interacting with your stakeholders.** Patients, pharmaceutical companies, scientific societies... all stakeholders are now represented on social media. Thanks to some networks, such as Facebook, Twitter and LinkedIn, it is possible to interact with your current stakeholders, as well as making new contacts, and letting your network know what your projects are.

• **Direct communication channels with patients.** Whether we like it or not, the internet is the first tool patients use to be informed. Although patient organisations usually are one of the first options, it’s more and more common to browse the web and check their social media profiles before contacting them. Social media gives us the possibility to communicate with patients in a more direct way and show them how we can help.

• **Participating in activities that you are not able to attend.** Asking questions or giving your opinion on behalf of your association, even when you are not attending an event which is happening far away, is now possible thanks to social media. Broadcasting events by streaming is more and more frequent and this makes it possible for users to ask questions via social media.

Having social media profiles is completely free but managing them in an appropriate way involves time and dedication to keep your profiles updated. In addition, networks such as Facebook or Twitter have tools to promote specific content at little cost. However, this toolkit focuses on the possibilities that social media can give you for free.
As we mentioned before, social media has a lot of advantages but also involves some risks. Before knowing how and why a particular social network should be used, you should take into account how risks can be reduced.

Social media puts us in a public position. That involves more visibility regarding our activities but also more impact if we say something inappropriate. Internet has the power to spread everything around the world very quickly and usually bad news spreads faster than good news. To avoid that happening and to get the greatest benefit from social networks, take into account the following tips:

- **Your organisation's social media profiles are not your personal ones.** This may seem obvious, but most problems on social media happen because of people giving personal opinions. Probably you already use your personal social media profiles and this gives you knowledge regarding how to use them and also things that work properly to reach more people. But if you are using your organisation's profile keep in mind that everything you say should follow some rules. Ascertain what the opinion of your organisation is concerning important topics, especially if they could be controversial.

- **Be careful in social media conversation when the topic discussed may cause a crisis situation.** There are many controversial topics that need to be discussed
but we should be careful to avoid situations that can have a negative impact on our organisation. If you are going to publish problematic information, prepare some statements in advance reviewed by your organisation’s board. As we will explain later, in social media every answer needs to be fast. Having a consensus about our position is not always easy and usually takes some time.

- **Don’t argue.** Keep an appropriate and polite position when disagreeing with others’ opinions. As a patient advocacy group, you will have to give your opinion regarding polemic issues. Sometimes other stakeholders will make public their opinion against your position in your own profile. Try to be as polite as you can and try to avoid confrontation. Make sure you have enough arguments and objective data before having any discussion. Use expressions such as “Thank you for giving us your perspective...”, “According to our experience, our position is...”, “This is a complex topic and all views are valid...”, “From our point of view...” to answer that comment without having a direct confrontation. Answer quickly and publicly and, after that, follow the conversation offline.

- **Be as clear as you can.** Try to write easy messages – some networks, such as Twitter, only allow a few words – and try to be as clear as you can. You will reach a lot of people with different profiles and different levels of awareness, and all of them should have the same idea about your message. If you are working within an organisation with an international or European perspective take into account that you are going to reach people with different native languages. Long and complicated messages are more difficult to understand for non-native speakers and can cause misunderstandings.

- **Verified data.** Try to share information mentioning your source, some specialist’s quote or any data that can support your statements. That will give you credibility and will help you to avoid issues derived from uncertain information.
• **Answer fast.** Information shared on social media is always fast and expires within a day or even earlier. Twitter, for instance, is more dynamic than Facebook, YouTube or Instagram. In a few hours your tweet will be very difficult to read because it will have moved down among other tweets. For that reason, replies should be fast, especially when you have a polemic question. Not answering could be understood as a lack of information or lack of interest by people with different opinions.

• **Be transparent and never delete bad comments.** If you make a mistake in your post, probably someone will realise it. If someone writes a reply, never delete your post or their comments. Doing so would mean you are trying to hide something and, as we mentioned before, information shared on social media is really fast. When the comment is deleted, probably more people than you think have already seen it. If you made a mistake, just say you are sorry and correct it. At the same time, reply to the people who made you aware of your mistake but don’t delete their comments. Just be as transparent as you can regarding your own mistakes.

If you have some offensive or aggressive comments in your social media profiles, you should delete them but write your own comment letting people know why you are doing that.
• **Make it visual.** We are always in a hurry and most people check their social media on their way home, going to work, etc... But if you see something that attracts your attention, don’t you stop a minute to watch it? Pictures, infographics or any other visual material will help you to get the attention of your target group. If you are talking about a conference, why don’t you include a picture of this event?

• **Live video.** Thanks to the new tools that social media platforms include, the information you share can be supported by different materials as we mentioned in the previous point. One of the new trends is the streaming of live video. That gives you a real-time engagement capable of increasing the audience size. Take into account that a live video is usually a transparent and a real content without any preparation and this will attract the attention of your followers.

But this kind of content has also some disadvantages to pay attention to. Unless there is a unique moment in time that needs to be captured live, recorded videos are usually more suitable. Live video tools are harder to manage and the result is always uncertain with a possible reputational impact. In addition, unedited content could be inaccurate. To avoid that happening, prepare everything you can before broadcasting a live video. The challenge is to be well prepared while seeming spontaneous. Choose the right
platform depending on the kind of video you would like to broadcast or the target group you want to reach. Check point 4, “Social media profiles” to know the benefits of each network.

- **The human side of your organisation.** Although the main information you share is data, pieces of advice to cope with the disease or information related to clinical trials, you can also show the human side of your organisation: the people and the inner workings of your association. Organisation of events, internal meetings... Showing hours and hours of hard work will make people know how much work is behind each activity that you develop.
4
Social media profiles

Twitter

Twitter is the most dynamic social network. It is based on tweets of 140 characters of text that are shown on your timeline. Although you have the option to approve who receives your Tweets, the best option to increase the visibility of your organisation is having a public profile.

Before getting started, check out some tips about how to use Twitter in the following summary. Here you will find some of the most important concepts when using this network. Twitter has a “Help centre” to help you make the most out of Twitter. Check this link to learn the basics: https://support.twitter.com.
We have selected the most important concepts about Twitter:

- **@.** The @ sign is used to call out usernames in tweets: “Hello @twitter!” People will use your @username to mention you in tweets, send you a message or link to your profile.

- **@username.** A username is how you are identified on Twitter, and is always preceded immediately by the @ symbol. For instance, Myeloma Patients Europe is @MyelomaEurope.

- **Follow.** Subscribing to a Twitter account is called “following.” A follow is the result of someone following your Twitter account. You can see how many follows (or followers) you have on your Twitter profile. To start following, click the Follow button next to the user name or on their profile page to see their tweets as soon as they post something new. Anyone on Twitter can follow or unfollow anyone else at any time, with the exception of blocked accounts.

- **Hashtag (#).** A hashtag is a label for content, any word or phrase immediately preceded by the # symbol. When you click on a hashtag, you’ll see other tweets containing the same keyword or topic. Anyone sharing content on a relevant topic can add the hashtag label to their message.

- **Like.** Liking a tweet indicates that you appreciate it. You can find all of your likes by clicking the likes tab on your profile. Tap the heart icon to like a tweet and the author will see that you appreciate it.

- **List.** From your own account, you can create a group list of other Twitter users by topic or interest (e.g. a list of advocacy groups, myeloma patients or healthcare professionals). Twitter lists also contain a timeline of tweets from the specific users that were added to the list, offering you a way to follow individual accounts as a group on Twitter.
• **Mention.** Mentioning other users in your tweet by including the @ sign followed directly by their username is called a “mention.” The term also refers to tweets in which your @username was included.

• **Pinned tweets.** You can pin a tweet to the top of your profile page to keep something important to you above the flow of time-ordered tweets. You can unpin that tweet at any time.

• **Retweet (RT).** A tweet that you forward to your followers is known as a retweet. Often used to pass along news or other valuable discoveries on Twitter, retweets always retain original attribution. You can share another user’s tweet with all of your followers by clicking on the retweet button.

• **Trends.** A trend is a topic or hashtag determined algorithmically to be one of the most popular on Twitter at that moment. You can choose to tailor trends based on your location and who you follow.

• **Tweet.** The act of sending a tweet. Tweets get shown in Twitter timelines or are embedded in websites and blogs. A tweet may contain photos, videos, links and up to 140 characters of text.

Now you know how Twitter works but there are some concepts that you should take into account to get the greatest benefit out of your profile. There are no rules that tell us how often you should tweet or the number of tweets recommended every day but as we mentioned before, Twitter is the most dynamic social network. Thousands of tweets are shared every day around the world. The short text format of this network makes quick conversations possible and a big number of messages are shared every minute. Unlike Facebook, most Twitter users have many accounts to follow and check hundreds of tweets every day thanks to the public character of this network. Your news should compete with profiles of celebrities, sports teams, singers... To have enough visibility in this social media, tweeting at least three or four times a day at different times of day is recommended. You can also have
visibility with fewer updates but your news could be hidden in the timeline.

Interact with other accounts, retweet tweets that mention your profile, mark them with likes or retweet any information that you consider interesting or useful for your followers. This also gives you visibility. Keep in mind that the replies to any question should be fast.

One of the things that will help you the most to manage your profile is having the Twitter app on your mobile phone. That will help you update your account and reply anytime. Although programming your tweets is not possible on Twitter yet, you can use some management tools such as Hootsuite or Tweetdeck to do so. This gives you the option to spend just 20 or 30 minutes every day in the morning to select, write and programme all the content you want to share throughout the day. Find more information about these tools under point 5, “Social media management tools: Hootsuite and Twitter wall”.

These tips may help you in the management of your account:

- **More information in fewer characters.** As you know you are not allowed to write more than 140 characters in one tweet. That includes links and mentions but not pictures anymore. In addition, pictures give you the option to mention other users there. So if you want to mention other users don’t do it in your tweet because that would mean less characters for the rest of the information. Add a picture and mention other users there. By doing so you will have the 140 characters for the information you want to share.

- **Any character before mentioning a user.** If a tweet starts with a username (e.g. @MyelomaEurope)
Twitter assumes that this tweet is part of a conversation between two users and automatically only includes that tweet in our timeline if we are followers of both accounts. Sometimes, as you can see in the example, we start a tweet with a mention without being part of conversation. To “trick” Twitter and get our tweet to be included in the timeline of all our followers, we can write any character before the mention. Usually users include a full-stop but you can include any other character or word.

- **Poll.** Twitter gives you the option of running a survey among your followers. You just have to click new tweet and then click in the symbol: 🥂 Write your question and different options to choose and tweet the poll. A twitter poll ends between 5 minutes and 7 days after it has been posted, depending on the duration set by the person who tweeted it. The winning choice is shown in bold. If you vote in a poll, you may receive a push notification alerting you to the final results. Your participation in a Twitter poll is anonymous. The username is not shown to others (neither the poll creator nor other participants can see who has voted).
Moments. Among the latest novelties that Twitter has added are the “moments”. Moments are stories or collections of tweets, photos and videos showcasing the very best of what’s happening on Twitter. You will recognise them with this symbol: ⚡ You can select moments categorised by news, sports, entertainment, fun, and more. If you would like to explore a Moment, click it to view the entire story. Scroll down through the Moment and click on any of the tweets to view the tweet detail. From there you can reply, retweet, and like the tweet.
Facebook

Facebook was born as a private network to share pictures, comments, news and be in touch with colleagues or friends. But its use has grown until it has become one of the most used networks even from a public perspective. That is why fan pages appear on Facebook. If you want your organisation to be present on Facebook, you should create a fan page instead of a personal profile. Pages are for brands, businesses, organisations and public figures to create a presence on Facebook, whereas profiles represent individual people. Anyone with an account can create a page or help manage one, if they have been given a role on the page like admin or editor. Take into account that pages and groups are not the same. A group is created by individuals and provides a space to communicate about shared interests with certain people. You can create a group for anything (family reunion, your after-work colleagues, your friends…) and customise the group's privacy settings depending on who you want to be able to join and see the group. A page, however, is always public and everybody is free to follow it. That means that you don't have to give them permission to join the group.

Facebook offers many options regarding privacy, notifications, tools... This toolkit focuses on the management of pages (not personal profiles or groups) which is the best option for any organisation. If you are interested in having more information regarding the options this network offers about fan pages as well as personal profiles, Facebook Help Centre may help you. In this link you have all the information regarding this network: https://www.facebook.com/help/.

As we mentioned before, to create a page for your organisation you will need a personal profile. That doesn’t mean that your followers can see the information you have in your personal profile or the photos or videos you post. You just need a personal profile to assume the role of administrator.

To create a page go to facebook.com/pages/create. In “settings” you could assign the
role of administrator to different profiles. To be named administrator you have to be a follower of that page. There are different roles that you can assign (you can assign those roles to more than one profile). According to Facebook Help Centre, there are 5 different types of roles for people who manage pages:

![Table of roles]

<table>
<thead>
<tr>
<th>Action</th>
<th>Admin</th>
<th>Editor</th>
<th>Moderator</th>
<th>Advertiser</th>
<th>Analyst</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage Page roles and settings</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Edit the Page and add apps</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create and delete posts as the Page</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Send messages as the Page</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respond to and delete comments and posts to the Page</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remove and ban people from the Page</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create ads</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>View insights</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>See who published as the Page</td>
<td>✓</td>
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</tbody>
</table>

Once you have all the roles defined and your home page customised with your logo and your description, you can start posting.

As we mentioned before, there is no golden rule that tells us how often you should update your Facebook or the number of posts recommended every day. Facebook was born as a network to share information within private circles such as friends, family... That is why users usually have fewer friends on Facebook than followers on Twitter, Instagram or other networks. This lets you have enough visibility just with one daily update of your home page. However, the use of all these networks changes constantly and you should try different strategies to find the visibility you need.

To evaluate the results that you have with every update in your page, you should check your page insights. Insights provide information about your page’s
performance, like demographic data about your audience and how people are responding to your posts. It is very important to understand concepts such as impressions and reach. According to Facebook Help Centre these are the definition of both concepts:

- **Impressions are the number of times a post from your page is displayed.** People may see multiple impressions of the same post. For example, if someone sees a page update in their News Feed and then sees that same update when a friend shares it that would count as two impressions.

- **Reach is the number of people who received impressions of a page post.** Reach might be less than impressions since one person can see multiple impressions. For example, if a person sees a page update in their News Feed and then sees that same update when a friend shares it that would represent a reach count of one.

Besides the “Insights” section, the “Publishing Tools” section could be very useful to manage your page. There you will find information on the reach and clicks of any publication.
There are some tools that may be useful for the management of your page:

- **Schedule content.** Facebook gives you the option to schedule content for a future publication. You just have to write the message you want to share and click on “Schedule”. This option appears in the pull-down menu close to “publish” (see the picture below). There you can choose the date and time you want the content to be published.

- **Create events.** One of the most useful tools for giving visibility to the event you are organising is the option “create event”. You will see this option in the landing page of your fan page. After you click in “create event” you can fill in the details of your event (dates, title, description...). You can also select whether you want your event to be public or want to invite just selected users.
• **Live video.** This option is only available in the Facebook for Android app or the Facebook for iOS app. You will not be able to broadcast live videos from your computer. If you want to do it on your app, you will find this option in the same space you use to update your profile clicking on “Go live”. The time limit for a live video session is 4 hours.

There are other networks that work in a similar way to YouTube, such as Vimeo, but YouTube is the largest social network to share videos. It is very well-known because it is capable of making a video very famous in a short period of time. Anyone can upload any video at any time.

As a patient organisation, you can use YouTube as a tool to collect your videos and share them in a very easy way. YouTube has many options. At YouTube Help Centre you will find all relevant information about them. This toolkit summarises the most useful options for your organisation. Take a look at these topics:
• **Simplify the process of sharing videos.** One of the most problematic things if you are not used to handling audio-visual material is the big size of any video. This makes it almost impossible to share them on social media profiles or even on your website. YouTube simplifies this process by storing your video files and providing you with a link to share them in a very easy way and also gives you the option of embedding the file in your web. Size limits on your video files are 2 GB per file and YouTube accepts a big variety of video formats: 

- .MOV
- .MPEG4
- .MP4
- .AVI
- .WMV
- MPEGPS
- .FLV
- .3GPP
- .WebM

• **Increase your video length limit.** By default, you can upload videos that are up to 15 minutes long. However, you can upload longer videos after verifying your account using a phone. YouTube needs to make sure that you are a real person to avoid spam. This platform only uses your phone number to send you a verification code and to check that it is not being used on many other accounts.

• **Share your video files.** This platform offers the option to share your videos by mail or share them directly on social media profiles. Social media metrics are a factor taken into consideration by Google when ranking pages. If you can create high-quality videos shared by others, you are signalling to Google that you are producing valuable content to your target audience.

• **Large storage capacity.** As mentioned before, video files usually have a very big size. This network allows you to store a big number of videos without having space problems.
• **Chose the privacy of every file.** Depending on how you are going to use each video, you can choose its privacy setting. Some options only allow the people you share the link with to watch the video. You can choose the best option for you when you upload the file.

You have three options:

✓ Public videos and playlists can be seen by and shared with anyone.

✓ Private videos and playlists can only be seen by you and the users you choose.

✓ Unlisted videos and playlists can be seen and shared by anyone with the link.
Once you have your video file uploaded, you will see these options:

**Add to:** you can include this file in different playlists within YouTube.

**Share:** YouTube gives you a link to share your video in more than 10 different social media networks. You just have to copy and paste that link or click in the social media you want to share the file. Another interesting option is “embed”. Embedding something in your website means having any element on your website but not hosted on your website, such as a YouTube video. The video is hosted on
the YouTube website but you can have it inside your own website. If you click in this option, the system gives you a small code to include this video within your website. Usually by copying the code given by YouTube and pasting in your page is enough to embed the video. However, every web is different and the way to embed elements is constantly changing.

The last option is sharing the video by email.

More: Using this option you will find it is possible to report the file, add a transcript or translation or check the statistics of your file. The last one will tell you the number of views of your video, time watched, subscriptions and shares.
5

Social media management tools: Hootsuite and Twitter wall

As we have seen so far, every network has different characteristics and tools. Some of them allow you to programme your updates, others provide you with statistics of your publications but all of them need to be updated frequently. However, the most common thing is that your organisation has profiles in different networks, at least Facebook and Twitter, and this can increase the time that you dedicate to social media.

There are different tools that can help you in the management of your profiles. We are going to highlight two of them: Hootsuite and Twitter wall.

**Hootsuite**

Hootsuite is a platform that provides you with tools to manage all your social profiles from the same platform and automatically find and schedule social content. One of the most useful characteristic of this tool is that you can manage it online. Unlike with other tools, you don’t need to download and install any file to use it.

This network offers different plans depending on what tools you are interested in. In this toolkit we are going to analyse the free plan that offers you the following characteristics:
• **Three social media profiles.** Within the free plan you can manage three social media profiles of different networks, for instance, your organisation's Twitter profile, your organisation's Facebook profile and your personal profile.

• **Basic analytics.** The most detailed reports about your profiles are available only in payment plans. However, Hootsuite gives the option to have basic analytics for free.

• **Autoschedule.** One of the most useful things is the option to schedule content. It is especially useful for Twitter because Facebook already provides you with that option.
Thanks to Hootsuite you will have in the same screen for your Twitter and your Facebook profiles and you can monitor the specific hashtags you may need to follow. This is especially useful when you are developing a project or a campaign linked to a hashtag. To monitor a hashtag in Hootsuite you should add the stream “search”. You will find this option at the end of the dashboard. Write the hashtag that you would like to monitor and click “search”. After that you will have a specific column with all the tweets that include that hashtag:
With the free Hootsuite plan you can also have basic analytics. Find this option in the bar you have at the right of the dashboard by clicking on “Analytics”. In the free plan you only are allowed to generate basic analytics of Twitter and Facebook and only one per profile. If you want to generate new analytics, you should delete the previous one. If not, the tool will ask you to upgrade your plan.

For instance, the report generated regarding Facebook profile contains the number of followers, the number of unique people who like your page, the number of unique people who like your page within the selected date range, page engagement, weekly total reach, daily likes and daily post feedback.

Twitter wall

Twitter wall is not a programme or an application. It is a concept that is becoming more and more common in public events, conferences or meetings. There are different tools that can put together all the tweets linked in a hashtag within a wall projected on to a screen. These tools are useful if you want to show the tweets that you are receiving to a specific hashtag. You can use most of them for free, but if you want to include your corporate colours, project a high numbers of tweets or modify the design of the wall probably you will have to upgrade your plan.

Projecting all your tweets not only shows your attendees the discussion that you
are generating within your community but also pushes them to participate in that online conversation while your event is happening. The more tweets you generate, the more visibility your organisation will have.

Although you will find a lot of tools to project a Twitter wall, we have selected these ones:

- **Wall of social**: https://www.wallofsocial.com
- **#tagboard**: https://tagboard.com
- **Visibletweets.com**: http://visibletweets.com
- **Twitterfall**: https://twitterfall.com
- **Walls.io**: https://walls.io

Be aware that some free plans could contain some publicity. Try your account before the event and check whether it shows publicity and what kind of publicity it may show to avoid uncomfortable situations. Some tools have cheap rates for a one-day event without advertisements, which may be advisable.
About Myeloma Patients Europe

Myeloma Patients Europe (MPE) is the largest European myeloma patient organisation formed by 40 myeloma patient organisations in nearly 30 European countries.

MPE is dedicated to provide education, information and support to member groups and to advocate at European, national and local levels for the best possible research and equal access to the best possible treatment and care. To this end, it seeks through its activities to:

- Build a professional and sustainable organisation.
- Facilitate development, capacity and sustainability of members.
- Encourage research and development of new effective treatments.
- Ensure the timely adoption of research outcomes or results and access to state of the art diagnostic tools and treatment.
- Encourage healthcare professionals to provide an excellent standard of care to patients and their families.
- Develop an evidence base for the needs and wants of patients and ensure access to high-quality information and psycho-social support.