

Practical guide to the EPF campaign for the 2014 European Elections

November 2013 – May 2014



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Welcome!

A warm welcome to the European Patients' Forum (EPF)'s guide to the campaign for the 2014 European Parliament Elections and new Commission 2014.

We are excited to share with you more information about our campaign and to provide you with some guidance on how to help shape your own campaign in concert with EPF and to promote the interests of the patients' community through your own networks.

These elections offer a fresh opportunity for the European Patients' Movement to encourage politicians and policy-makers to commit to a healthier Europe.

Through our campaign we want to remind decision-makers that we, as European citizens with chronic disease, are voters and that we want them to reflect a patients' perspective in their work.

When we will cast our vote, we will therefore be confident about voting for a healthier Europe, where patients are seen as a part of the solution for high-quality, sustainable and cost-effective healthcare.

We hope we can count on you for your support!

Warmest greetings for an inspiring and successful campaign.

Anders Olauson, EPF President

Nicola Bedlington, EPF Director



What is the Campaign about?

The EPF Campaign “Patient + Participation = Our Vote for a Healthier Europe” unites patient advocates nationally and at EU level to encourage decision-makers to act towards a healthier Europe for patients.



PATIENTS + PARTICIPATION

The word “participation” comprises the ideas of perspective, empowerment, equal access and involvement. Patients’ participation means that

- a/ patients’ views matter as we are experts ‘by experience’ of our chronic disease and then we know what works and what does not,
- b/ patients need to be empowered and to equally access healthcare to be full partners in the management of our condition and according to our individual capacities and situation,
- c/ patients need to be involved in designing more effective healthcare and in research.

= OUR VOTE

“Our vote” means that this campaign will not be driven only by our people here in Brussels, but rather our 61 members and their networks throughout Europe. Collectively we represent the interests of a large constituency of 150+ million people living with chronic diseases across the European Union. And a high proportion of voters for the next EU elections.

FOR A HEALTHIER EUROPE

These elections are a big milestone for patients in Europe. The stakes are much higher than in 2009 - the political and economic agenda for patients, and indeed for all of us, has evolved much since then. We know from our members throughout Europe that the challenges their patients constituencies are facing are enormous. Fundamental inequalities and lack of access prevail, even more as our population ages. We need to ask ourselves, what kind of society do we want, for us, and for the future -and health is absolutely central to this.

With our campaign, we want to create a sense of urgency and real imperative to address the fundamental roadblocks to patients’ access to proper healthcare. We want to demonstrate how patients can be part of the solution to make health systems more effective and quality-oriented.

In other words, a healthier Europe.

Why is it important for you to engage in the campaign?

Asking this question is similar to asking “Why should patients care about the EU?” Alastair Kent addressed this issue on our blog and provided a fair answer:¹

“Taken at face value, it might seem that there is little reason for patient and patient organisations to get involved in the elections for the European Parliament that will take place next May. After all, the provision of health care is the responsibility of the member countries of the EU, and European Institutions have only a very limited authority to intervene in areas related to public health, so getting involved requires a lot of effort for very little potential benefit.”(...)

*“I believe that the concerted efforts of organisations such as the European Patients’ Forum to influence regulation and set policies that are patient friendly at the Commission and at the European Parliament have been **vital in getting us to where we are today**. Patient advocacy at the EU level has been an **effective tool in bringing about positive change** for those with unmet medical needs in Europe.”*

*“The elections next year provide an opportunity for candidates to hear and listen to the patient voice and in so doing to help **set the priorities for the new parliamentary session**. Whether or not they get the chance to listen depends on patients and patient organisations make the effort to share their issues and concerns with them. It will be **up to all of us** to decide whether we want to get involved or are we content to leave it to ‘someone else’ to do it.*

“In my view we should all support the efforts of the EPF and make sure that the next European Parliament is alive to the patient and family perspective on issues that affect us all.”

EPF recognises that each patient organisation has unique needs and requires different approach to make the most of the 2014 EU Elections. This guide aims to offer a framework with advice and core material to prepare the period ahead of the elections. You are encouraged to develop messaging and local activities that work for your own purpose, to reach as wide audience as possible. However this should be part of a general campaign to strive for including a patients’ perspective into decision-makers’ work.

¹ Extract of the article written by Alastair Kent, Director of Genetic Alliance UK, on EPF Blog: <http://www.eu-patient.org/blog/?p=180>

How to engage in the campaign?

To make this campaign a success, we need to work together. We appreciate that all of our members have different needs and priorities and encourage you to consider incorporating our campaign into your existing outreach campaigns, with the theme “Patients + Participation = Our Vote for a Healthier Europe”.

TAKE PART IN THE “SHOW US YOUR COMMITMENT” CHALLENGE!

Engage Together ! The patient community as a whole benefits from individual commitment. But only by committing all together, we can make this campaign a bigger movement.

EPF invites you to take an active part in the campaign and to “show us your commitment”.

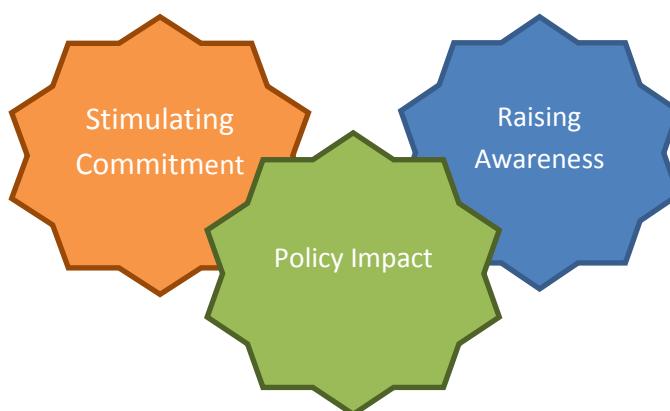
Let's take up the challenge together:

STEP 1: Support the EPF campaign by undertaking one or several of the actions listed below.

STEP 2: “share with us your commitment”: compile quick testimonies of your actions (screenshots on Facebook/Twitter, links, copy of the letter, etc.), tick the corresponding boxes in the ‘engagement checklist’ (annex 4) and send it to us (camille.bullet@eu-patient.eu).

STEP 3: The EPF Board will select a number of “Success stories” of EPF member organisations having shown most support to the EPF Campaign.

STEP 4: Tell your story! The member organisations selected will showcase their success stories on how to support the Campaign and patients' rights during the EPF event “The Night Before the Elections” that will take place during our AGM.



PLATFORMS AND MESSAGING WHERE TO SHOW YOUR COMMITMENT

We provide an overview here of suggested platforms and messaging that you could use to engage your own members.

SIGN THE MANIFESTO

- Go to the following link and sign the online form to formally support our campaign (the form takes a few seconds to appear):
<http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/I-support-EPF-Campaign/>
- Encourage your member organisations having signed the manifesto.
- Ask everyone you know to sign the online form. Ask 10 of your friends, family and colleagues to sign the petition. Email everyone you know with a link to the online form and put it on your website, on your blog, on your Facebook page and Tweet about it!



DISTRIBUTE THE MANIFESTO

- Print and disseminate the EPF Manifesto at your events
- Use the campaign materials –images, Facebook cover, etc.- to illustrate your own articles, posts, etc.

Manifesto available at: www.eu-patient.eu/library/Manifesto-all-languages/



TAKE PICTURES OF YOUR MEMBERS WITH THE MANIFESTO

- Take pictures of your members with the manifesto, post them on social media, and send them to us!
camille.bullet@eu-patient.eu
- Accompany the picture with the name and organisation of the person holding it so we can identify our supporters!



TALK ABOUT THE CAMPAIGN AT YOUR EVENTS

- At your events, **invite an EPF speaker** to introduce the EPF campaign.
- At a conference, **add a few slides** about the EPF campaign to your talk.
- These slides are available [here](#) and contain basic information so feel free to edit them for your own needs and do give us a feedback about what response you got: camille.bullet@eu-patient.eu.

Link to PowerPoint template: http://www.eu-patient.eu/Campaign-2014-EU-Elections/Documents/TEMPLATE_EU-elections-2014-campaign.pptx



ENGAGE ON FACEBOOK

- Post an article on the campaign!
- ‘Like’/‘Share’/‘Comment’ our posts about the campaign.
- Have a look at the annex of this document to see some examples of Facebook posts!
- Share the EPF Facebook page on your own organisation’s Facebook page and ask friends to “like” it!

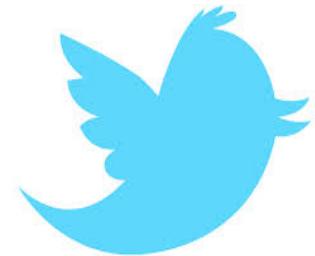
Our page: www.facebook.com/EuropeanPatientsForum



TALK ABOUT THE CAMPAIGN ON TWITTER

- Use the hashtags **#patientsvote** and/or **#epf2014** to tag your tweets about the EPF campaign
- Use **@eupatientsforum** to address us directly
- Have a look at the annex of this document to see some examples of Tweets!

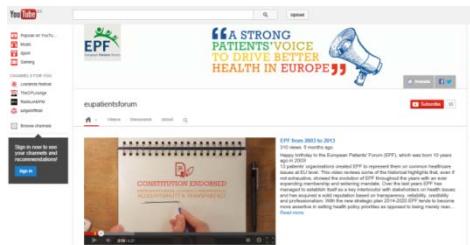
Our Twitter account: <https://twitter.com/eupatientsforum>



TALK ABOUT THE CAMPAIGN ON YOUTUBE

- Watch our campaign videos and share them on your website, in your newsletter and on your social media platforms (Facebook, Twitter)

Our YouTube channel: www.youtube.com/eupatient



TALK ABOUT THE CAMPAIGN ON YOUR WEBSITE!

- Write a news article on your website/blog to raise awareness about the EPF campaign within your patient community. Explain the campaign and why you support it!
- Have a look at the annexes of this document to see an example of article!



CONTRIBUTE TO EPF BLOG

- Share your personal testimonial as Alastair Kent has done, about how greater **empowerment and involvement** have contributed to make healthcare more cost-effective and of high-quality
- Share your opinion about a specific area of the campaign

Next steps: Read and comment existing articles on **EPF Blog**:

<http://www.eu-patient.org/blog/>

Share our blog articles on your website, in your newsletter and on your social media platforms.



SEND PRESS RELEASE TO JOURNALISTS

- Send a press release to journalists to let them know about the campaign and your support to it.
- Is your local, regional or national media is talking about the campaign? Has it taken over one of your press releases? Let us know!
- Have a look at the annexes for a sample press release for your media contacts!



SEND A LETTER TO A REGIONAL OR NATIONAL POLITICIAN

- Write a letter to call on your government and national representatives to support this campaign and commit to a patients' perspective in their work.
- Have a look at the annexes for a sample letter to politicians which you can personalise and send.



SEND LETTERS TO MEPS OR CANDIDATES TO THE EUROPEAN ELECTIONS

- Send a letter to an MEP going for re-election or a candidate to the European elections asking to commit to the campaign at EU level



EPF Campaign's key messages

PATIENTS' VIEWS MATTER.

We, patients of all ages and conditions, live with our chronic disease every day and regularly use health services. We have a unique perspective on healthcare. We are experts on what works for us and what does not. We can therefore guide decision-makers on how to offer good quality care that is also cost-effective.

We ask European decision-makers to engage patients collectively and pro-actively through patient organisations in policy decision-making to ensure that all policies and practices reflect patients' real-life needs, preferences and capabilities.

EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY.

We want to be full partners in the management of our conditions according to our individual capacities and situation. We need to be empowered to do so. Empowerment starts with tailored high-quality information and health literacy, to enable us to make informed choices about our treatment and care.

Empowered patients are good for health systems. We take responsibility for our care in equal partnership with health professionals. We also take preventive measures, seek earlier diagnosis and adhere to treatment, which can reduce healthcare costs in the long run.

We ask European decision-makers to adopt an EU strategy on patient empowerment, including an action plan on health literacy and high quality information for patients on all aspects of our care.

Breaking down access barriers.

Access to quality healthcare is a basic EU citizens' right. Yet it is still not a reality for many of us – a situation made worse by the economic crisis. Access means the availability of treatment, but also its affordability. Access also means non-discrimination. All patients in the EU deserve equitable access to care.

Breaking down health inequalities is also good for health systems. If we do not get the care we need at the right time, we may develop more severe illness, reducing our capacity to live a full and productive life and increasing health, social and economic costs. All of us deserve a chance to contribute to society.

We ask European decision-makers to support an EU initiative on equitable access to healthcare for all European citizens, through a multi-stakeholder Platform

Patient involvement = healthier Europe

We, patients, as healthcare users, need to be involved in designing more effective healthcare and in research to deliver new and better treatments. Meaningful patient involvement in research will lead to treatments that provide real value. Patient-centred, integrated healthcare will lead to better quality of life for us and our carers, and more cost-effective, equitable and sustainable health systems for all. In other words, a healthier Europe.

We ask European decision-makers to develop a clear framework for **patient involvement across the spectrum of health research**, through the entire cycle of the innovation chain.

Finally, we call on the next Health Commissioner to ensure patients' right is part of his/her portfolio.

Quotable quotes²

Anders Olauson, EPF President:

"These elections are a big milestone for patients in Europe. We know from our members throughout Europe that the challenges patients constituencies are facing are enormous. Fundamental inequalities and lack of access prevail, even more as our population ages. We need to ask ourselves what kind of society do we want, for us, and for the future -and health is absolutely central to this. This is what we fight for in our Campaign and Manifesto."

"With our campaign, we want to create a sense of urgency and real imperative to address the roadblocks to patients' access to proper healthcare. Access to healthcare is a basic EU citizens' right - yet it is still not a reality for many of us, a situation made worst by the economic crisis."

"The patients' role in healthcare must be transformed from being passive recipients to active and engaged actors of our own health management."

"If you look at the benefits of patient empowerment and involvement for healthcare systems, they are numerous: avoidable hospitalisations, more effectively allocated healthcare resources, better quality care throughout the "patient journey", more adherence to treatment and better informed and motivated patients."

Tonio Borg, Commissioner for Health at DG SANCO³:

"I congratulate you and welcome your initiative. I fully agree with you, that patients' views matter; and that empowered patients are an asset for the economy. Indeed patient empowerment contributes to the success of a healthcare system: by putting patients in the driving seat we enable them to participate in improving their own health."

² Those quotes are extracted from notes addressed at the campaign launch event on 1 October 2013.

³ Full version of the speech: http://ec.europa.eu/commission_2010-2014/borg/docs/01102013.pdf

Annexes

ANNEX 1 - SOME EXAMPLES OF TWEETS AND POSTS:

Tweet 140 characters on Twitter	Post a message on Facebook
[Your organisation] supports the #epf2014 #patientsvote campaign of @eupatientsforum. Sign the manifesto here: http://goo.gl/9EXm3H	[Your organisation] supports the EPF campaign for the 2014 EU Elections. Do you support a healthier Europe for patients too? Link: http://goo.gl/9EXm3H
Patients + Participation = [Your organisation] will vote for a Healthier Europe on 22-25 May 2014. And you? #patientsvote	Patients + Participation = [Your organisation] will vote for a Healthier Europe on 22-25 May 2014. And you? Link: http://goo.gl/9EXm3H
We call on decision-makers to engage #patientorganisations in decision-making to ensure ALL policies reflect our needs #patientsvote	2014 EU Elections: we call on decision-makers to engage patients collectively and proactively through patient organisations in decision-making to ensure all policies reflect our needs Link: http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/
We call on decision-makers to adopt an EU strategy on patient empowerment #healthliteracy for patients #patientsvote	2014 EU Elections: we call on decision-makers to adopt an EU strategy on patient empowerment including an action plan on health literacy and high-quality information for patients on all aspects of healthcare Link: http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/
We call on decision-makers to support an EU initiative on equitable access to healthcare for all European citizens #epf2014 #patientsvote	2014 EU Elections: we call on decision-makers to support an EU initiative on equitable access to healthcare for all European citizens through a multi-stakeholder platform Link: http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/
We call on decision-makers to develop a clear framework for patient involvement in health research #epf2014 #patientsvote	2014 EU Elections: we call on decision-makers to develop a clear framework for patient involvement in health research, through the entire cycle of the innovation chain Link: http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/
We call on decision-makers to ensure that #patientsrights is part of the next health Commissioner's portfolio #epf2014 #patientsvote	2014 EU Elections: we call on decision-makers to ensure that patients' rights is part of the next health Commissioner's portfolio Link: http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/

ANNEX 2: SAMPLE LETTER FOR NATIONAL REPRESENTATIVES

Address of national ministry of health
Minister of health

Place, Day Month Year

Dear name of your Minister,

**Patients Campaign for the 2014 EU Elections:
Patients Call for National Support to Commit to A Patients' Perspective at European Level**

We are writing on behalf of the European patient community to ask for your support in the upcoming EU Elections on 24-25 May 2014 to ensure that a patients' perspective is included at EU level in all policies.

More specifically, we would like to work with you towards:

Equity and Access

It is unacceptable that in the 21st century Europe patients can still expect different health outcomes depending on where they live, their nationality, socio-economic circumstances, etc. We need EU action to build a Europe committed to better and more equal health outcomes.

- ✓ Support the creation of an EU Multi-Stakeholder Platform on Access and Equity, tasked with developing concrete workable solutions to the unacceptable health inequalities experienced by patients, particularly those who are most vulnerable, throughout Europe on a daily basis.

Patient involvement

Patient groups have, because of our unique experience and expertise, a legitimate and invaluable role in contributing to policy development, research and innovation and cohesion policy across our continent but also at national, regional and local levels. Their input ensures that investment is targeted where it will make a real difference to patients.

- ✓ Ensure that meaningful patients' involvement is embedded in all EU policies with a health and/or social component.
- ✓ Support patient involvement across the spectrum of health research in the Horizon 2020 framework programme and the Health Programme.

Patient empowerment

Empowered, health literate patients and citizens are a key element of high-quality, patient-centred health systems of the future that meet societal expectations and respond to people's needs in a way that is cost-effective and sustainable.

- ✓ Advance a comprehensive and coherent strategy at EU level to support and patients' empowerment, embracing quality information and health literacy.
- ✓ Ensure that patients' rights are part of the next Health Commissioner's portfolio.

Non-discrimination

Equity for patients also means non-discrimination – in healthcare as well as in other areas of life, such as education, employment and services.

- ✓ Support the submission of a Commission proposal for a Framework Directive on Non-discrimination that addresses discrimination on the grounds of health status, reflecting the health provisions of the Charter on Fundamental Rights of the EU.

Finally, we call on you to support our Patients' Manifesto "*Patients + Participation = Our Vote for a Healthier Europe*" (see attached), that was launched on 1 October 2013, to enable Members of the future European Parliament to commit to a patients' perspective in their work to drive better health and work towards a fairer society in Europe.

We look forward very much to our strong dialogue and cooperation on these crucial issues. If you wish to support our Manifesto and to show your commitment to our work towards a healthier Europe for all citizens, please inform me by e-mail.

Thank you for your support.

Yours sincerely,

Your name, organisation and signature

ANNEX 3: SAMPLE PRESS RELEASE FOR YOUR MEDIA CONTACTS

PRESS RELEASE

Media contacts

Your media contact + email + telephone

Cynthia Bonsignore, EPF Communication Officer:

cynthia.bonsignore@eu-patient.eu, +32 (0)2 280 23 35

Patient Campaign for the 2014 EU Elections

Patient + Participation = Our Vote For A Healthier Europe

Place, date – The [name of your organisation] joins the European Patients' Forum (EPF) with the campaign entitled “*Patient + Participation = Our Vote For a Healthier Europe*” ahead of the 2014 European elections. We encourage policymakers to commit to putting patients at the centre of healthcare throughout Europe.

[Quote from your organisation's president]

“The European Parliament Elections and new Commission 2014 offer a unique new opportunity for the European Patients’ Movement to encourage politicians and policy makers at all levels to commit to act towards patient-centred, integrated healthcare that will lead to better quality of life for us and our carers, and more cost-effective, equitable and sustainable health systems for all. In other words, working towards a healthier Europe”, said Anders Olauson, EPF President

Through this campaign we highlight patients as part of the solution in addressing fundamental roadblocks in patients' access to high-quality, effective and sustainable healthcare.

Patients need to be empowered to be full partners in the management of their conditions, according to their individual capacities and situation. We need also to make equal access to quality healthcare a reality for all of us, even in times of economic crisis.

In our Manifesto, we therefore call on policy-makers to:

- Engage patients collectively and pro-actively through patient organisations in policy decision-making to ensure that all policies and practices reflect patients' real-life needs, preferences and capabilities.
- Adopt an EU strategy on patient empowerment, including an action plan on health literacy and high quality information for patients on all aspects of our care.
- Support an EU initiative on equitable access to healthcare for all European citizens, through a multi-stakeholder Platform
- Develop a clear framework for patient involvement across the spectrum of health research, through the entire cycle of the innovation chain.
- Ensure that patients' rights is part of the next Health Commissioner's portfolio

[As an alternative, you can provide a specific case study from your country illustrating one of the key four messages of the campaign]

We represent a high proportion of voters for the next EU elections. We hope our voice will be heard by decision-makers and that they will add a patients' perspective in their work.

More information about the campaign is available on <http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/>.

ENDS

About EPF

The European Patients' Forum (EPF) was founded in 2003 to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU. EPF currently represents 61 member organisations - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organisations. EPF reflects the interests of an estimated 150 million patients affected by various diseases throughout Europe.

EPF's vision for the future is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

The EPF strategic goals focus on areas such as health literacy, health and social care sustainability, patients' involvement, patients' empowerment, strong and effective patients' organisations and discrimination on the grounds of health status.

www.eu-patient.eu

[A word about your organisation]

ANNEX 5: EXAMPLE FOR AN ARTICLE ON YOUR WEBSITE

The European Patients' Forum (EPF) has launched their 2014 campaign: Patients + Participation = Our Vote for a Healthier Europe. [Your organization here] has committed to making this campaign a success.

Because of our experience and unique perspective on healthcare, our views matter! The EPF campaign focuses on engaging patients collectively and proactively through patient organisations like ours. This will help ensure that policies and practices better reflect our real-life needs, preferences and capabilities.

We also know empowered patients are an asset to society. We support EPF's call for an EU strategy on patient empowerment via health literacy initiatives and the availability of high-quality information to patients. This will allow us to make informed choices about our healthcare and become equal partners with health professionals.

Equal access to quality healthcare is our right. We deserve treatment that is both available and affordable to us on a non-discriminatory basis. Equal healthcare access will give us all an opportunity to contribute to society. We recognize that the 2014 EPF campaign needs our support in pushing for an EU initiative on equitable access to healthcare for all European citizens.

Finally, we, as patients, need to be involved in designing more effective, patient-centred healthcare through research. This will help the healthcare industry to develop effective treatments that will improve the quality of life for us and our carers, as well as create a more cost-effective treatment system.

Our essential support is key to the success of these objectives! By sharing EPF's manifesto for the 2014 European elections (found [here](#)), participating in the campaign on social media, engaging with our local media and asking our politicians to support the campaign, we can help ensure that the patient voice is heard in the 2014 elections. For ideas on how you can become personally involved in promoting 2014 campaign, check out [EPF's guide](#) on engaging in the campaign.

ANNEX 6: YOUR ENGAGEMENT CHECKLIST

We want to hear about your activities! Get in touch with our Membership Officer at camille.bullet@eu-patient.eu and provide her this checklist after you have ticked the boxes below corresponding to the actions that you have completed with your organisation.

Tick this box if done!	Action
<input type="checkbox"/>	Sign the EPF online Manifesto
<input type="checkbox"/>	Encourage your members to sign the EPF online Manifesto
<input type="checkbox"/>	Like/share on Facebook & Retweet on Twitter
<input type="checkbox"/>	Take pictures of you/your members with the manifesto and post it on Twitter/Facebook
<input type="checkbox"/>	Talk about the campaign at your events
<input type="checkbox"/>	Print and disseminate the EPF Manifesto at your events
<input type="checkbox"/>	Post about the campaign on Facebook
<input type="checkbox"/>	Tweet about the campaign
<input type="checkbox"/>	Post articles about the campaign on your website
<input type="checkbox"/>	Send press release about the campaign to journalists
<input type="checkbox"/>	Achieve to have one article coverage in media
<input type="checkbox"/>	Contribute to the EPF blog with articles about the campaign
<input type="checkbox"/>	Send a letter to/Contact a regional or national politician asking to commit to the campaign at national level
<input type="checkbox"/>	Achieve to have one signature from a regional or national politician of the EPF online Manifesto
<input type="checkbox"/>	Send a letter to/Contact an MEP going for re-election or a candidate to the European elections asking to commit to the campaign at EU level
<input type="checkbox"/>	Achieve to have one signature from an EU candidate of the EPF online Manifesto