

Practical Guide to the EPF Patient Empowerment Campaign

How you can make a difference!

May 2015 – June 2016



Patients prescribe E⁵ for sustainable health systems.



Supported by:

Robert Bosch **Stiftung**

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1. The “Patients Prescribe” Campaign



WHAT IS PATIENT EMPOWERMENT?

Patient empowerment is a process that helps people gain control over their own lives and increases their capacity to act on issues they themselves define as important.

Empowerment has both an individual and a collective dimension: at individual level, it is the extent to which patients and their families or caregivers, whenever appropriate, participate in decisions related to their condition and contribute to organisational learning through their specific experience as patients. At collective level, patients, through their representative organisations, contribute to shaping the health care and social system through involvement in health and social policy-making, organisation, design and delivery.

For more information, please visit our [website](#).

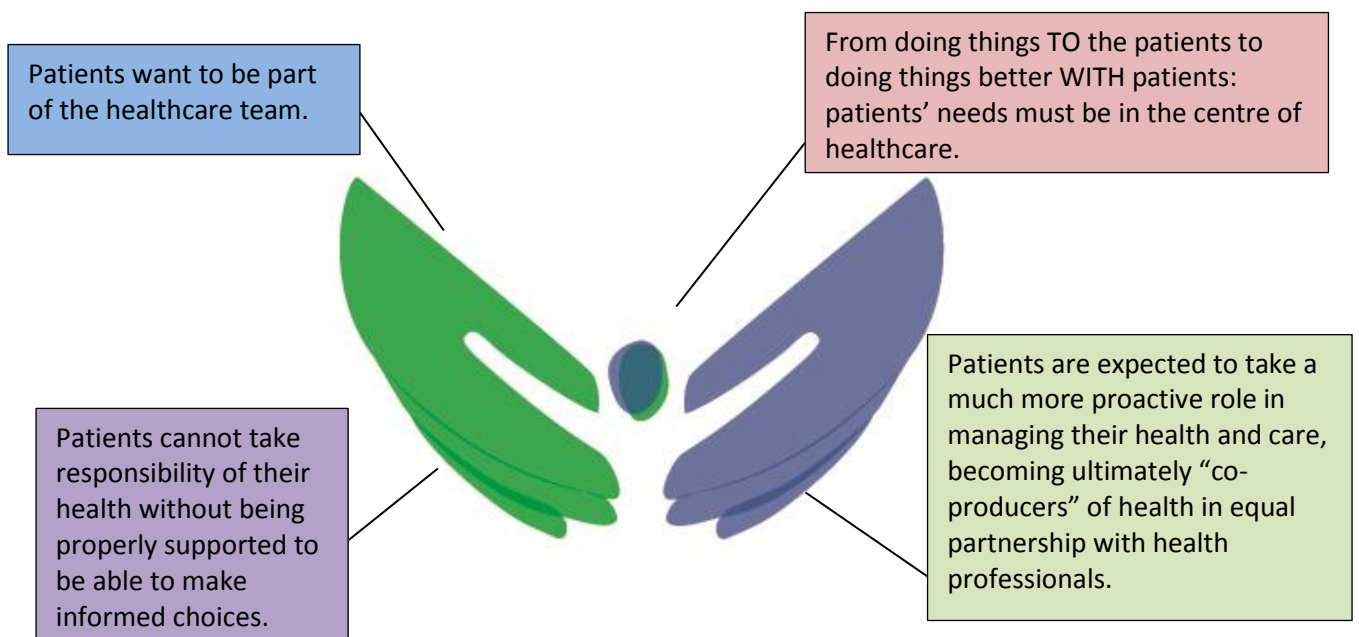
THE CAMPAIGN TAGLINE

PATIENTS PRESCRIBE E⁵ FOR SUSTAINABLE HEALTH SYSTEMS

The aim of the Patient Empowerment Campaign is to build the momentum for the real empowerment of patients in Europe and to promote the development and implementation of policies, strategies and healthcare and social services that empower patients to be involved in the decision-making and management of their condition.

CAMPAIGN LOGO

The logo represents the campaign’s identity and the concepts behind patient empowerment:



CAMPAIGN MESSAGES

“Patients prescribe E⁵ for sustainable health systems” is the tagline of the EPF campaign. It demonstrates that patients are active people who can, if supported and according to their individual capabilities and situation, make a positive difference to the sustainability of healthcare systems.

The five “E” of Empowerment stand for:



Education: Patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.



Expertise: Patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.



Equality: Patients need support to become equal partners with health professionals in the management of their condition.



Experience: Individual patients work with patient organisations to represent them, and channel their experience and collective voice.



Engagement: Patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services



WHAT ARE WE CALLING FOR?

EPF is leading the Patient Empowerment Campaign and will work in concert with the health community to promote understanding of what patient empowerment means from the patient perspective among decision-makers and health stakeholders.

As part of the campaign, EPF will publish a Charter on patient empowerment and a multi-stakeholder Roadmap for Action, including good practices and strategy for concrete follow-up actions to be taken by all stakeholders.

Patient empowerment is acknowledged to be good for the society, bringing benefits that can lead to better health outcomes and patient satisfaction and contribute in shaping better, more sustainable healthcare services.

Important factors leading to patient empowerment include well-informed, health literate patients who participate in the development and delivery of healthcare



services and who are able to work together with health professionals to ensure that the healthcare provided is personalised to their needs¹. Evidence also shows that poor health literacy accounts for 3-5% of total healthcare costs at system level² and shared decision-making leads to 25% reduction of elective surgeries³.

However, currently, there is no European strategy on patient empowerment and a lack of accessible, reliable and understandable health-related information that meets patients' needs, although core quality criteria have been defined at European level⁴.

This is why we call on EU policy-makers to:

1. Adopt an EU strategy on patient empowerment to achieve a real impact on the ground for the benefit of patients and society as a whole.
2. Act upon the 'Roadmap for action' that will be developed in November 2015 with concrete actions to promote the empowerment and meaningful involvement of patients as equal and respected partners in healthcare.
3. Commit to patient empowerment as it is defined in the 'Patient Empowerment Charter' that will be published in November 2015.
4. Develop an action plan on health literacy to ensure meaningful information and resources are available to patients and enable them to make informed choices about their treatment and care.
5. Support EPF in the identification and implementation of good practices in patient empowerment and involvement to ensure that they are replicated and scaled up at EU level. EPF is currently developing a repository including practical tools to facilitate shared decision-making between patients and health professionals; effective self-management interventions etc.

SAVE THE DATES!

Below, we have summarised the key milestones of the campaign and when they will take place for you to note in your calendar!

You are welcome to organise your own event in your country and we will gladly attend! Go to [page 13](#) for more information on how to organise your event.



¹ "Empowering patients in the management of chronic diseases"

http://ec.europa.eu/health/patient_safety/docs/empathie_frep_en.pdf

² "The costs of limited health literacy: a systematic review", Eichler K, Wieser S, Bruegger U, Int J Public Health, 2009;54(5):313-24.

³ Coulter A, Parsons S, Askham J (2008)

⁴ Final Conclusions and Recommendations of the High Level Pharmaceutical Forum, October 2008, available at http://ec.europa.eu/enterprise/sectors/healthcare/files/docs/pharmaforum_final_conclusions_en.pdf

What?	When?	Where?
Launch of the Patient Empowerment Campaign	20-21 May 2015	Brussels, Belgium
MEP roundtable, release of the Patient Empowerment Charter and Roadmap for action	November 2015	European Parliament, Brussels, Belgium
EPF Annual General Meeting	March 2016	Brussels, Belgium
Close of the campaign, Exhibition , High Level Debate	June 2016	European Parliament, Brussels, Belgium

WITH WHOM WILL WE CAMPAIGN?

...WITH YOU!

We can make patient empowerment a reality only if we work together.

EPF wants to ensure that YOU have everything you need to campaign for patient empowerment. You are the voice of the campaign in your specific environment. With your help, we can communicate the campaign messages and actively get involved at an EU and national level.

THE ROLE OF EPF MEMBERS

EPF members are the driving force of this campaign across the EU. With your help, we can deliver our messages to all EU stakeholders and decision-makers and raise awareness about the campaign and patient empowerment at EU level and national level.

European Disease-specific Organisations

As a disease-specific organisation, each EPF member has different needs and expectations. For this reason, we have kept the campaign messages very general, so that you can re-use and adapt them in your disease-specific area.

National Coalitions

National Alliances are umbrella patient organisations representing a wide range of patients and diseases organisations within a specific country.

Your role in the Patient Empowerment Campaign is to help communicate and coordinate the campaign at national level. We encourage you to use the campaign material in any way you wish and to develop you own tools based on their countries' standards.



Go to [page 10](#) to see all the ways in which you can help.

FRIENDS OF THE PATIENT EMPOWERMENT CAMPAIGN - YOUR VITAL ROLE!

The Patient Empowerment Campaign is organised and driven by patient organisations who are actively engaged in the campaign, however the campaign needs everyone who supports patient empowerment and would like to participate: carers, researchers, health professionals, regulators, the healthcare industry, insurers and anyone else who is interested in a better EU health system.

As a friend of the campaign you can help us communicate our key messages and goals with simple and easy to do activities. Go to [page 10](#) to see how you can engage in the campaign.



2. How to engage in the campaign?



EPF recognises that everyone has unique needs and will have a different approach to make the most of the Patient Empowerment Campaign. This guide aims to offer a framework with core material on how you can engage in this campaign while adapting to your organisation’s own approach. You are encouraged to develop activities that work for your own purpose, to reach the widest audience possible.

Choose how you want to engage in the campaign depending on the level of difficulty of each action:

1. Wow, this is so easy! (page 10)

This is the easiest way you can engage in the campaign, but equally important! It only requires from you to have access to small things like an email account, a social media account or just a mobile phone.



2. Sure, I can do this! (page 12)

This includes more difficult actions, but still nothing you cannot do!



3. Challenge accepted! (page 13)

This is the most difficult level for the most engaged campaign supporters. It requires rather more time and resources but we promise you, it’s worth it.



WOW, THIS IS SO EASY!

SUPPORT THE CAMPAIGN PLEDGE

There is both an online and a print version of the pledge which you can support. You can choose one of the two ways or you can do both!

Print version:

- Take pictures of you (alone or in team) with the [pledge](#).
- If you are on social media, post it there and mention us so that we can share it (Facebook: /EuropeanPatientsForum, Twitter: @eupatientsforum) or send the picture to us (with the name and organisation of the person holding it) at communications@eu-patient.eu so that we can post it for you!
- Ask your friends, members and network to do the same.



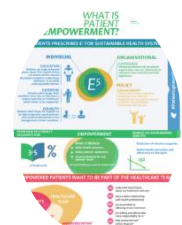
Online version:

- Sign the online pledge [here](#) and leave your message on how you commit to support the campaign.
- If you are on social media share the link to the pledge and ask your network to sign it too!



DISTRIBUTE THE CAMPAIGN LEAFLET

- Print the leaflet and disseminate it at your events and to your contacts.



- If you cannot find the leaflet in your language, it means that we need your help to translate it! Contact us for more information on how you can do this.
- Send it to your contacts through email, newsletter or social media.
- Let them know why it's important. Go to [page 4](#) for more information.

CAMPAIGN ON SOCIAL MEDIA

Do you or your organisation have a Facebook account? Then you can:

- Follow EPF on Facebook: [/EuropeanPatientsForum](#)
- Share EPF Facebook page on your own organisation's page and ask your friends to "like" it!
- Post information about the campaign (find some example Facebook posts you can use at [page 18](#)).
- Share campaign information and news from [EPF website](#).
- Like, share and comment EPF campaign posts.

Don't forget to mention us in your posts so that we can share them as well – [/EuropeanPatientsForum!](#)



You have a twitter account? Then you can:

- Follow EPF on Twitter: [@eupatientsforum](#)
- Use the official campaign hashtag **#PatientsprescribE** to tag your tweets about the campaign (find some examples of Tweets on [page 17](#)).
- Retweet EPF tweets to help us spread the word.

Don't forget to use [@eupatientsforum](#) to address us directly so that we can share your tweets!



YouTube:

- Follow EPF on YouTube: [/eupatient](#).
- Watch our campaign videos and share them on your website, in your newsletter and on your social media platforms!
- Do you want to make a video for our YouTube channel, saying what patient empowerment means to you? Go to [page 12](#) for more information.



TALK ABOUT THE CAMPAIGN AT YOUR EVENTS

- At your events, you can speak about the campaign or invite an EPF speaker to do it. Contact communications@eu-patient.eu to organise this.
- At a conference, add a few slides about the EPF campaign to your talk, available [here](#) – feel free to edit them for your own needs.



SURE, I CAN DO THIS

TRANSLATE THE CAMPAIGN MATERIAL

- The only way to ensure that the campaign material reaches everyone in the EU, is by translating it, and for this, we need you! Contact us at communications@eu-patient.eu to receive the campaign material for translation.

SHOW YOUR SUPPORT ON YOUR WEBSITE

- Write a news article on your website/blog/newsletter to raise awareness about the EPF campaign within your patient community. Explain the concept of patient empowerment and encourage your audience to engage with us. Find a template on how to write an article on [page 21](#).
- Use the campaign material: include the logo/banner on your website. Find all the relevant campaign material [here](#).



CONTRIBUTE TO EPF BLOG

- Are you a patient and you self-manage your disease? A health professional and you wish to work with empowered patients? Share your own testimonial about patient empowerment, or your opinion about a specific area of the campaign.
- There are already many articles: read and leave your comment: <http://www.eu-patient.org/blog/>
- Share our blog articles on your website, in your newsletter and on your social media platforms.
- Contact EPF at communications@eu-patient.eu to receive more information on how to contribute to the blog.



SEND A PRESS RELEASE TO A JOURNALIST

- Send a press release to your local journalists to inform them about the campaign, bringing your own perspective on patient empowerment. Find a sample press release for your media contacts at [page 20](#).
- Is your local, regional or national media talking about the campaign? Has it been a focus in one of your press releases? Let us know – send us an email at communications@eu-patient.eu



MAKE A VIDEO!

- Make a video with your members or, why not, a selfie video to tell us why you support the campaign or what do you ask from the decision makers.
- Post it on social media and don't forget to use #PatientsprescribeE
- Send it to us so that we can share it as well!



PROVIDE GOOD PRACTICES

You run a campaign, events, studies related to patient empowerment? Share your activities with us so that we can support each other and show the united voice of the health community on this topic. Contact us at communications@eu-patient.eu.

CHALLENGE ACCEPTED!

ORGANISE YOUR OWN EVENT

An event at National level is a great way to raise awareness about the campaign, so if you have the resources we strongly encourage you to do so! At the event, make sure that you distribute printed campaign material (leaflets, logo and pledge) and take lots of pictures to let everyone know what happened at your event. Make sure to also take pictures with the campaign [pledge](#) and send them to us! Last but not least, have fun!



Please contact EPF at communications@eu-patient.eu to coordinate this – we can arrange a speaker, or send you some campaign material.

INFLUENCE DECISION MAKERS

For patient empowerment to actually happen and for concrete actions to take place, we need the help of policy shapers and makers. Not only in Brussels but in all EU countries – this is why we need your help to transfer our messages to your representatives.



Here are some examples on how you can contact them:

Send letters to decision makers/MEPs

- First, find out who they are and their contacts from the [European Parliament](#) website. You can then:
- Write a letter to call on your government and national representatives to support this campaign at national level and encourage their European peers to adopt an EU strategy on patient empowerment (find a letter template which you can personalise and send at [page 19](#)).
- You are from the, Luxembourg, the Netherlands, Slovakia or Malta? These countries have the forthcoming EU Council Presidencies – urge your government to put patient empowerment on the agenda.



Set up a meeting with decision-makers

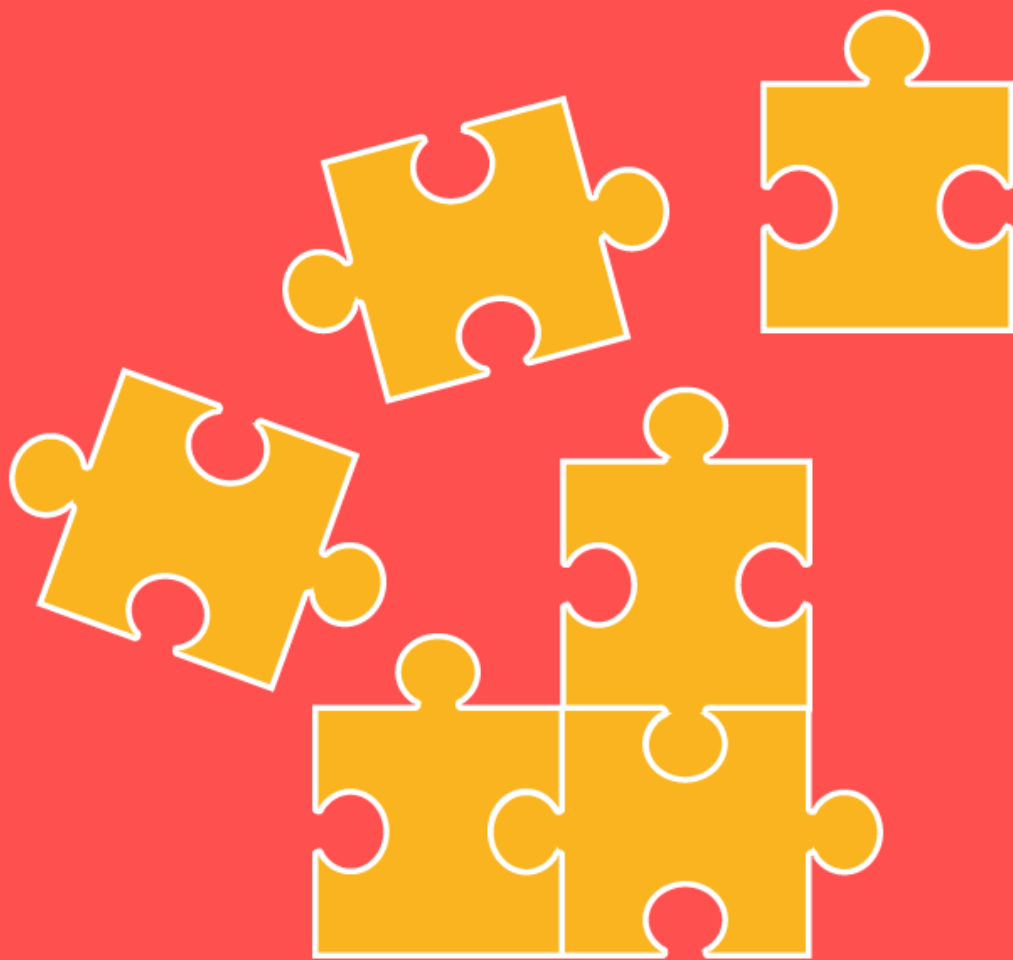
- Call their office and ask to make an appointment. And don't take no for an answer!
- Know why you want to meet them: we call for an EU strategy on patient empowerment.

- Know what you want to discuss: take with you the leaflet that explains why this is important, the pledge and key messages.
- Make sure you let them know how to get involved in the campaign.
- Send an email to thank them afterwards and send them a [link](#) to the online pledge.
- Post photos on social media and don't forget to tag them.

Together, let's prescribe E⁵ for Sustainable Health Systems!



3. Annexes



ANNEX 1: YOUR ENGAGEMENT CHECKLIST!

We want to hear about your activities! Complete the checklist below, check the box of each action when done, scan it and send it back to us at communications@eu-patient.eu .



Action	Done
Wow, this is so easy!	
We will tweet/retweet about the campaign at least times	<input type="checkbox"/>
We will post about the campaign on Facebook times	<input type="checkbox"/>
We and at least of our members will take a picture with the campaign pledge	<input type="checkbox"/>
We will talk about the campaign at [name event] on [date] in [city/country]	<input type="checkbox"/>
We will disseminate the campaign leaflet during the [name event]	<input type="checkbox"/>
We will sign the online campaign pledge	<input type="checkbox"/>
Sure, I can do this!	
We will post campaign articles on our website/blog	<input type="checkbox"/>
We will speak about the campaign times in our newsletters	<input type="checkbox"/>
We will send press releases to journalists	<input type="checkbox"/>
We will achieve to have articles' coverage in media	<input type="checkbox"/>
We will contribute to EPF blog times	<input type="checkbox"/>
We will make one short video to show our support on the campaign	<input type="checkbox"/>
Challenge accepted!	
We will contact/send a letter to regional or national politicians	<input type="checkbox"/>
We will achieve to have politicians take picture with the pledge	<input type="checkbox"/>
We will set a meeting with decision maker to discuss about the campaign	<input type="checkbox"/>
We will organise events for the campaign	<input type="checkbox"/>
We will write a statement to show our support	<input type="checkbox"/>

ANNEX 2: EXAMPLES OF TWEETS

Feel free to use them as they are or to modify them to your organisations' needs:

Tweets (up to 140 characters)

[Your organisation] supports the #PatientsprescribE campaign of @eupatientsforum. <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We, patients with [chronic condition] support @eupatientsforum campaign #PatientsprescribE for sustainable health systems <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We, patients from [country] support @eupatientsforum campaign #PatientsprescribE for sustainable health systems <http://www.eu-patient.eu/campaign/PatientsprescribE/>

#PatientsprescribE E5 for sustainable health: #Education #Expertise #Equality #Experience #Engagement @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We call on decision-makers to adopt a strategy on patient empowerment and support #PatientsprescribE campaign of @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We call on policy-makers to commit to patient empowerment! #PatientsprescribE @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We are part of the healthcare team – we ask healthcare professionals to treat us as equal partners #PatientsprescribE @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @eupatientsforum campaign #PatientsprescribE because we want to be partners in the management of [your organisation's disease] <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We ask decision-makers to ensure that patients' needs are in the centre of EU #health systems #PatientsprescribE @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We with [your organisation's disease] need to access the right information to make decisions about our health #PatientsprescribE <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We can make decisions about our health in partnership with the healthcare professionals – no one else can do it for us. #PatientsprescribE @eupatientsforum

We self-manage our #health already everyday – we just need support to do this #PatientsprescribE @eupatientsforum <http://www.eu-patient.eu/campaign/PatientsprescribE/>

[your organisation] already signed @eupatientsforum pledge for #PatientsprescribE. And you? Sign it here: <http://www.eu-patient.eu/campaign/PatientsprescribE/take-action/>

ANNEX 3: EXAMPLE OF FACEBOOK POSTS

Just like tweets, you can copy and paste them directly or modify them as you like:

Facebook posts

[Your organisation] supports the EPF campaign “Patients prescribe”. Empowered patients are good for health systems! <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @EuropeanPatientsForum #PatientsprescribE campaign and we call on decision-makers to join us to work together towards patient empowerment <http://www.eu-patient.eu/campaign/PatientsprescribE/>

[Your organisation] and the patients from [country], support @EuropeanPatientsForum campaign for sustainable health systems <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @EuropeanPatientsForum campaign for patient empowerment and as patients we prescribe E5 for sustainable health: Education–Expertise–Equality–Experience – Engagement. <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @EuropeanPatientsForum campaign and we call on policy-makers to engage patients collectively and proactively in decision-making to ensure all policies reflect our needs. <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We, patients, want to be involved in the decisions regarding our health and be part of the healthcare team. We ask healthcare professionals to support @EuropeanPatientsForum campaign towards patient empowerment <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @EuropeanPatientsForum 2015 campaign because we want to be partners in the management of [your organisation’s disease]<http://www.eu-patient.eu/campaign/PatientsprescribE/>

We support @EuropeanPatientsForum “Patients prescribe E5 for sustainable health” campaign and we ask decision-makers to ensure that patients’ needs are in the centre of EU health systems <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We with [your organisation’s disease] need access to the right information to be able to make decisions about our health. We call on decision-makers to support @europeanpatientsforum patient empowerment campaign to ensure that. <http://www.eu-patient.eu/campaign/PatientsprescribE/>

We can self-manage our health – no one else can do it for us. We support @europeanpatientsforum “Patients prescribe E5 for sustainable health” campaign to ensure that we have the resources to do more.

<http://www.eu-patient.eu/campaign/PatientsprescribE/>

ANNEX 4: SAMPLE LETTER FOR NATIONAL REPRESENTATIVES

Here is a sample letter for your national representatives. You can use it as it is just by filling in your organisation's details, or you can adjust it according to your organisation's needs.

[Address of national ministry of health]

[Minister of health]

Place, Day Month Year

Dear [name of your Minister],

Concern: European Patients' Forum ~Patients Prescribe" campaign for Patient Empowerment:

We are writing on behalf of the European patient community to ask for your support on the development of an EU-wide strategy on patient empowerment. Empowered, health literate patients are a key element of high-quality, patient-centred health systems of the future that respond to people's needs in a way that is cost-effective and sustainable.

More specifically, we would like to work with you to ensure that the five "E" of patient empowerment is a reality for all patients in EU:

- **Education:** patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.
- **Expertise:** patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.
- **Equality:** patients need support to become equal partners with health professionals in the management of their condition.
- **Experience:** individual patients work with patient organisations to represent them, and channel their experience and collective voice.
- **Engagement:** patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services

We ask you to:

- ✓ Push for the adoption at EU level, of a strategy on patient empowerment.
- ✓ Commit to concrete activities to promote the empowerment and meaningful involvement of patients as equal and respected partners at national level.

Finally, we call on you to support our [pledge](#), to show your commitment to our work towards patient empowerment. If you wish to further support and engage in the campaign, please contact the European Patients' Forum at communications@eu-patient.eu.

We look forward very much to our strong dialogue and cooperation on these crucial issues.

Thank you for your support.

Yours sincerely,

[Your name, organisation and signature]

ANNEX 5: SAMPLE PRESS RELEASE FOR MEDIA

FOR IMMEDIATE RELEASE

[Name of your organisation] joins the European health community to call for EU Action on Patient Empowerment

Place, Date– The [name of your organisation] joins the European Patients’ Forum (EPF) with the campaign entitled “*Patients prescribe E⁵ for sustainable health*”. We encourage policymakers to adopt a strategy on patient empowerment and commit to meaningful patients involvement in the design of the healthcare system.

[What your organisation is doing on patient empowerment]

[Quote from your organisation’s president]

#PatientsprescribE

“*Patients prescribe E5 for sustainable health systems*” is the tagline of the EPF campaign to demonstrate that patients are active people who can, if supported and according to their individual capabilities and situation, make a difference for the sustainability of healthcare systems. The five “E” of Empowerment stand for:

- **Education:** patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.
- **Expertise:** patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.
- **Equality:** patients need support to become equal partners with health professionals in the management of their condition.
- **Experience:** individual patients work with patient organisations to represent them, and channel their experience and collective voice.
- **Engagement:** patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services.

The purpose of this campaign is to promote understanding of what patient empowerment means from the patient perspective among political decision-makers and health stakeholders. The outcomes of the campaign will contribute to the development of a Charter of Patient Empowerment and a multi-stakeholder Roadmap for Action to be released in November 2015.

ANNEX 5: EXAMPLE ARTICLE FOR YOUR WEBSITE

The European Patients' Forum (EPF) has launched their "Patients Prescribe" campaign: [Your organisation here] supports this campaign as patient empowerment represents [your views] to us.

With this campaign, we aim to promote understanding of what patient empowerment means from the patient perspective among political decision-makers and health stakeholders. We want them to commit to concrete activities to promote the empowerment and meaningful involvement of patients as equal and respected partners in healthcare.

"Patients prescribe E⁵ for sustainable health systems" is the tagline of the campaign to demonstrate that we are active patients and we can, if we are supported and according to our individual capabilities and situation, make a difference for the sustainability of healthcare systems.

The five "Es" of Empowerment are:

Education: Patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.

Expertise: Patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.

Equality: Patients need support to become equal partners with health professionals in the management of their condition.

Experience: Individual patients work with patient organisations to represent them, and channel their experience and collective voice.

Engagement: Patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services


Patient empowerment can contribute to better quality of life for us and our carers, and more cost-effective, equitable and sustainable health systems for all. Especially for patients in [your country], patient empowerment can [insert few words].

More information: <http://www.eu-patient.eu/campaign/PatientsprescribE/> or contact EPF at communications@eu-patient.eu.

EUROPEAN PATIENTS' FORUM

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-  [/EuropeanPatientsForum](https://www.facebook.com/EuropeanPatientsForum)
-  [@eupatientsforum](https://twitter.com/eupatientsforum)
-  [/eupatient](https://www.youtube.com/eupatient)

