

Call for Expressions of Interest: Engaging Patients within PARADIGM activities/workshops

06/11/2018



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1. Purpose of the Call

The **European Patients' Forum (EPF)** is launching a call for expressions of interest to select a **Pool of Patient Advisors** (hereafter 'the Pool') to participate in the PARADIGM project, (H2020-JTI-IMI-2016-10) number 777450 (hereafter "PARADIGM") workshops/activities.

EPF wishes to receive expressions of interest from **patients or patient representatives** interested in **contributing and participating to thematic workshops within the PARADIGM project to represent the patient community perspective**. A pool of patients and/or patient representatives will be selected and assigned to the workshops according to their expertise and background, in particular with respect to patient engagement (PE) in medicines research and development. Read below more information about EPF and PARADIGM project.

Please note that [EATG](#), [Alzheimer Europe](#) and [EURORDIS](#) are also members of PARADIGM and may have different procedures for involving patients in the PARADIGM activities. If you are a member of any of these organisations and would like to take part in a PARADIGM activity or workshop, please contact them directly.

2. EPF - General Information

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 **70+ members**, which are **national coalitions of patient's organisations and disease-specific European platforms**. EPF reflects the voice of an estimated 150 million patients affected by various chronic 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.

3. PARADIGM – General Information

[PARADIGM](#) stands for **Patients Active in Research and Dialogues for an Improved Generation of Medicines** and is funded by the **Innovative Medicines Initiative (IMI)** and **EFPIA members**. It is a **public-private partnership** launched on 1 March 2018 and will run for **30 months**, until August 2020.

The IMI project is led by the European Patients' Forum (EPF) and is a consortium that comprises of patient organisations, regulatory bodies, universities, non-profit organisations, Small & Medium Enterprises (SMEs), pharmaceutical companies and pharmaceutical trade associations.

Patient engagement in biomedical research is key for better health outcomes. PARADIGM is built on existing tools, is filling knowledge gaps and is building a sustainable roadmap for patient engagement.

The project was conceived on three **key decision-making points of the development of medicinal products**:

- The **setting of research priority**,
- The **design of clinical trials** and
- The **early dialogue with regulators and HTA bodies**.

4. Description of the activities

The PARADIGM workshops have been designed to **engage patients and patient representatives in several topics related to patient's engagement in medicines development**. Find below a few examples of themes. Please note that other topics could be identified throughout the life of the project.

- Identifying Gaps/Needs in Patient Engagement
- Metrics for monitoring and evaluating Patient Engagement
- Co-designed recommendations and resources for Patient Engagement
- Code of conduct and guidance for Patient Engagement
- Systematization of meaningful Patient Engagement
- Sustainability of the Patient Engagement ecosystem

The present call meets the needs of patients and patient representatives who have the motivation and apply expert-level knowledge across the whole spectrum of the medicine research and development process, with a take home learning and return on the experience for the patient advisors.

5. Description of tasks

The selected **Pool of Patients** will provide a high-quality and essential contribution for PARADIGM. As a **Patient Advisor**, you will be required to:

- **Attend a face-to-face meeting or an e-meeting with EPF staff to go over the workshop agenda and expected outcomes;**
- **Prepare an innovative presentation presenting patient perspective;**
- **Present at the PARADIGM workshop/activity,**
- Provide a **feedback report after the workshop** (no later than 30 days after the workshop/activity) and,
- Additional tasks may be agreed in advance depending on the needs of the workshop/activity.

The Patient Advisor will work under supervision of a dedicated EPF staff member. They will directly report to EPF of his/her activity, pre- and post- workshop activities (i.e. preparation and reporting) will be conducted via teleworking.

6. Time Frame

The timings below are indicative. Final timelines for the different tasks relating to the workshop will be agreed during an initial meeting with EPF.

	Step	Description	Timing
Selection of the pool of patients	1	Launch the Call for Expression of Interest	6/11/2018
	2	Close of the Call	30/11/2018
	3	Selection of candidates	December 2018
Involvement of patient Advisor in specific activities	4	Invitation to the workshop/activity	Day - 6 weeks before the workshop/activity
	5	Briefing meeting	Day - 4 weeks before the workshop/activity
	6	Workshop/Activity	D0
	7	Follow-up report from the patient advisor	D+4 weeks following the end of the workshop/activity

7. Participation in the Call Procedure

7.1 REQUIREMENTS

The PARADIGM activities/workshops have been designed to **include patients and patient representatives' perspectives in several topics related to patient engagement in medicine development**. They will focus on topics of interest for patients and patient advocates who have the motivation and apply expert-level knowledge across the whole spectrum of the medicine research and development process, with a take home learning and return on the experience for the patient advisors.

Please note that [EATG](#), [Alzheimer Europe](#) and [EURORDIS](#) are also members of PARADIGM and may have different procedures for involving patients in the PARADIGM activities. If you are a member of any of these organisations and would like to take part in a PARADIGM activity or workshop, please contact them directly.

Applications are open to individuals who meet all the following requirements:

1. **Be an experienced Patient Advocate** (affiliated or not to a patient organisation)
 - a. Employee (representing an organisation) or volunteer of a patient organisation or,
 - b. Patient with a chronic and/or lifelong illness/condition or,
 - c. Family member/carer of a patient with a chronic and/or lifelong illness/condition.

2. **Have a keen interest in the medicines research and development process and patient engagement.** Applicants need to demonstrate they have a genuine interest in and sound understanding of medicines' research and development processes.
3. **Possess working knowledge of English.** The workshops will be in English and it will require a high level of interaction and communication in English. Accordingly, applicants must have a working knowledge of English, at least at an upper-intermediate level or B2 [Common European Framework of Reference for Languages \(CEFR\)](#).

7.2 INFORMATION REQUIRED

Applicants should submit the following documents:

- ✓ Application form to be completed in [Survey Monkey](#);
- ✓ Curriculum Vitae to be uploaded via [SurveyMonkey](#) (4 pages maximum);
- ✓ Declaration of Interest to be signed directly in the [online form \(Survey Monkey\)](#);
- ✓ Any available supporting documents attesting knowledge in the required sector (authorship/co-authorship of articles, certificates etc, speaking engagements at events- ISPOR, HTAi, DIA etc)

Document applications must be sent through the [Survey Monkey form](#). Please contact Camilla Habre if you have any questions (camilla.habre@eu-patient.eu).

Closing Date for acceptance of application is 30 November 2018 at 23:59 (CET)

[Fill in this survey](#) to submit your documents and information.

If you are selected among the Pool of Patients, we would like to inform you that your participation will depend on the PARADIGM activities topics, dates and relevance. In other words, even if you are selected as a Patient Advisor, we cannot ensure that you will be contacted to participate to the activities/workshops.

7.3 SELECTION CRITERIA LIST

All applications received by the deadline of **Friday 30th November at 23:59 (CET)** will first and foremost undergo an "eligibility check" to make sure all eligibility criteria set out above are fulfilled.

Applicants who fall short of fulfilling all eligibility criteria will be notified by email. The decision taken by EPF will be final and not subject to appeal.

Those applicants that pass the initial eligibility screening will be evaluated for their specific motivation, skill-set and experience. PARADIGM is committed to ensuring that the evaluation process meets the highest standards for transparency.

The selection criteria are as follows:

1. **Quality of the individual motivation for applying. Please provide answers to the following questions to support your answer:**
 - What are your objectives or goals by participating in a PARADIGM workshop/activity?

- What do you expect to gain from the workshops?
- How will your participation in the workshops/activities contribute to and improve medicines research and development in your region or country and/or Europe?
- How will your patient community or the disease you represent benefit from your participation in the workshops/activities?
- How does your personal and/or professional experience prepare you for the workshops?

2. Experience/knowledge related to Patient Engagement in medicines R&D and to PARADIGM activities/workshops topics. Find below a few examples of thematic. Please note that other topics could be identified in the upcoming months.

- Identifying Gaps/Needs in Patient Engagement
- Metrics for monitoring and evaluating Patient Engagement
- Co-designed recommendations and resources for Patient Engagement
- Code of conduct and guidance for Patient Engagement
- Systematization of meaningful Patient Engagement
- Sustainability of the Patient Engagement ecosystem

3. Experience in interacting/collaborating with other stakeholders active in the R&D process of medicines and that could be related to the IMI-PARADIGM project.

Current knowledge and experience in medicines’ research and development could be used as a selection criterion. PARADIGM aims to engage patients and patient advocates who have the motivation and apply expert-level knowledge across the whole spectrum of the medicine research and development process, with a take home learning and return on the experience for the patient advisors.

The table below summaries the selection criteria and score percentages which eligible applications will be assessed against:

Selection criterion	Score
Quality of the individual motivation for applying	40
Experience related to PARADIGM workshops/activities topics	40
Experience in interacting/collaborating with stakeholders	20
TOTAL	100

8. Terms of Payment

A Memorandum of Understanding (MoU) will be signed at least 4 weeks before the activity/workshop and will frame the participation of the Patient Advisor within the project.

The remuneration of the Patient Advisor will be 400 €/day. This is a fixed rate for each activity/workshop and is not subject to revision. The Patient Advisor will need to submit a time sheet attached to the activity/workshop report.

The payment will be made within 30 days of receipt of a request for payment / invoice as applicable and after receipt of the activity/workshop report and time sheet produced by the Patient Advisor.

All travel and subsistence costs will be paid by EPF – this would include pre-booking flights and accommodation and reimbursing local travel and subsistence costs.

All claims will be submitted using EPF documents and following EPF procedures. All original invoices, receipts and boarding passes must be submitted with the claim.

Costs incurred in preparing and submitting applications are borne by the applicants and cannot be reimbursed.

9. Confidentiality and Conflict of Interest

The Pool of Patients Advisors undertakes that they will not at any time, either before or after the termination of this agreement, use or disclose or communicate to any person confidential information relating to the affairs of EPF. This restriction shall continue to apply after the termination of the agreement without limit in point of time.

To ensure the independence of terms of their contract, the selected Pool of candidates will sign a declaration certifying that they have no conflict of interests in relation to the tasks to be undertaken and undertake to inform EPF should this status change.

EPF will process the data submitted by candidates for the purposes of selection, in compliance with GDPR according to its [Privacy Policy](#). We will treat your data with the utmost care and take all appropriate steps to protect it.

10. Contracting Authority

European Patients' Forum (EPF)

Chaussée d'Etterbeek, 180

1040 Brussels - Belgium

www.eu-patient.eu

11. Contact Person

Camilla Habre, Project Officer at camilla.habre@eu-patient.eu