



**IPPOSI PATIENT EDUCATION  
PROGRAMME IN HEALTH  
INNOVATION**

**2019 Programme**

**A Guide for Applicants**

## ABOUT IPPOSI

IPPOSI – The Irish Platform for Patient Organisations, Science and Industry – is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of health innovation. Through more than 12 years of forging close links and alliances between Patients, Clinicians, Scientists, Industry, Regulators and Policy Makers, IPPOSI has been the primary contact and conduit for patients interested in engaging more actively in the R&D process. IPPOSI is also recognised as a key influencer contributing towards the overall development of Health Research Policy in Ireland. IPPOSI membership is open to all groups with an interest in healthcare and research and development; Patient Representatives, Academic, Science or the Healthcare Industry. More information about IPPOSI can be found on [www.ipposi.ie](http://www.ipposi.ie)

## ABOUT IPPOSI PATIENT EDUCATION AND TRAINING

Through our Education and Training actions, IPPOSI aims to equip our patient members and their communities with the tools and knowledge to empower patients' and lay people, and to promote their meaningful involvement in health innovation. To date, we have focused on the areas of clinical development, safety of medicines and access to treatments but plan to expand into other areas of relevance to patients. IPPOSI also encourages patients and patient advocates to apply the knowledge and skills they acquire through IPPOSI activities in three main areas according to their experience and aspirations:

- **Patient Representation:** We encourage IPPOSI Patient Members to actively engage in representing a patient perspective in the health innovation process by interacting with scientific committees, HTA agencies, regulatory bodies, industry, academia and other relevant stakeholders in Ireland and at the EU level.
- **Communication:** We encourage IPPOSI Patient Members to contribute to raising awareness on patient involvement in health innovation amongst their communities, including patients whose voices are seldom heard, and the lay public. Examples of activities include writing articles / press releases; organising press conferences; facilitating cooperation with the media; being a spokesperson on TV / Radio programmes; utilising social networks and blogs.
- **Education/Training:** We encourage IPPOSI Patient Members to play facilitation / training roles by supporting the dissemination of patient education and information programmes for other patient communities and the general public through their patient networks. Examples of activities include: providing training to patient advocates; leading workshops; running information sessions for people interested in participating in trials.

This patient education programme was conceived through IPPOSI's experience within EUPATI (see below), in partnership with the following Irish education partners:

- **University College Dublin Clinical Research Centre**
- **The Health Products Regulatory Authority (HPRA)**
- **The Department of Pharmacology & Therapeutics, Trinity College Dublin, in association with the National Centre for Pharmacoeconomics (NCPE) and the Health information and Quality Authority (HIQA)**

## ABOUT EUPATI

IPPOSI plays a leading role in the European Patients' Academy on Therapeutic Innovation (EUPATI), a pan-European initiative which provides scientifically reliable, objective, comprehensive information to patients and citizens on Medicines Research and Development (R&D). IPPOSI is responsible for coordinating over 18 EUPATI National Platforms in 18 different countries and is the host of the [EUPATI National Platform in Ireland](http://www.eupati.eu). More information about EUPATI can be found on [www.eupati.eu](http://www.eupati.eu)

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## Introduction

This Guide is designed for applicants for the IPPOSI Patient Education Programme in Health Innovation. Its aim is to assist applicants in preparing the documents for the application process which consists of an application form (mandatory) a motivation letter (mandatory) and a letter of reference (optional).

We strongly urge all applicants to read this guide before filling out and submitting the application package. Should you have any further questions, please contact us at [info@ipposi.ie](mailto:info@ipposi.ie)

## Eligibility Criteria

Applications are open to all individuals who fit any of the following profiles (the list does not intend to give an order of priorities):

- Employee or volunteer of a patient organisation in the Republic of Ireland
- Patient with a chronic and/or lifelong illness/condition who is not affiliated with a patient organisation and who participates or intends to participate in projects / activities / committees etc. to represent his/her personal experience as a patient and/or the perspective of an informal group of patients
- Family member / carer (not affiliated with a patient organisation) of a patient with a chronic and/or lifelong illness/condition who participates or intends to participate in projects / activities / committees/etc. to represent patients.

Applications will be accepted from candidates living in the Republic of Ireland.

**The patient education programme is available for approximately 25 participants and is structured into three modules. It is mandatory that participants complete all three modules. A selection procedure will identify the 20-25 participants who will begin the programme by attending the introductory session in mid-January, 2019 (Dublin city Centre venue – TBC).**

## Application Deadline

Please complete your application by no later than **midnight (24:00 Dublin) on 18 November 2019.**

You complete your application by:

- a) [Filling out this application form](#)
- b) Emailing your motivation letter (mandatory) and reference letter (optional) to [info@ipposi.ie](mailto:info@ipposi.ie)

## How to Apply

Applications for the IPPOSI Patient Education Programme should be submitted online via the following link: [ONLINE APPLICATIONS FORM](#). Please make sure that you answer each question as detailed as possible. Advice on how to complete the different sections of the application form is available at the end of this document. **We regret that incomplete applications or applications received after the deadline cannot be reviewed.**

**We thank you for your interest in the IPPOSI-led patient education programme and we look forward to receiving your application.**

## About the IPPOSI-led Patient Education Programme

### 2019 Programme

The 2019 programme will begin with a full day face-to-face session on the week starting January 14th, 2019 (Dublin city Centre (precise date, time & venue TBC)). The morning session will be an introductory training on the elearning platform (Moodle) delivered by IPPOSI. The afternoon part will be the first face-to-face training session for the 'Understanding Clinical Trials' Module.

The 2019 programme will last for the period of mid-January 2019 until mid-November 2019 and will cover the following three modules:

#### **Module 1: Understanding Clinical Trials**

**- delivered by the University College Dublin Clinical Research Centre**

**Duration: 10 weeks (TBC)**

**1<sup>st</sup> face-to-face session: Week beginning January 14<sup>th</sup>, 2019 (half day)**

**2<sup>nd</sup> face-to-face session: Week beginning February 25<sup>th</sup> 2019 (half day)**

**3<sup>rd</sup> face-to-face session: Week beginning March 25<sup>th</sup>, 2019 (half day)**

After completing the module on understanding clinical trials, participants will be able to:

- Apply their knowledge at the leading edge of patient focused clinical research
- Contribute to the design of methodologically robust and statistically valid clinical research protocols
- Appraise, evaluate and enhance clinical research protocols, ensuring the highest quality research outputs
- Understand clinical trial regulations and appreciate the importance, practical use and evolution of these regulations.
- Possess excellent communication and presentation skills, appropriate to the multidisciplinary clinical research environment
- Collaborate with academic partners and industry to complete clinical research programmes
- Commit to continuous lifelong learning and further diffusion of their clinical research expertise

#### **Module 2: Regulatory Affairs, Medicinal Product/Device Safety and Pharmacovigilance**

**- delivered by the Health Products Regulatory Authority (HPRA)**

**Duration: 10 weeks (TBC)**

**1<sup>st</sup> face-to-face session: Week beginning April 29<sup>th</sup>, 2019 (half-day)**

**2<sup>nd</sup> face-to-face session: Week beginning May 27<sup>th</sup> 2019 (half-day)**

**3<sup>rd</sup> face-to-face session: Week beginning July 1<sup>st</sup> 2019 (half-day)**

**Venue: Health Products Regulatory Authority, Block A, Earlsfort Centre, Earlsfort Terrace, Dublin 2**

After completing the module on regulatory affairs, medicinal product/device safety, pharmacovigilance, participants will be able to:

- Critically review the current National and EU regulatory requirements (pre and post-authorisation) for medicinal products and medical devices
- Discuss the role and importance of Regulatory Agencies and other stakeholders, in particular patients/patient organizations, throughout the lifecycle of a medicinal product
- Describe the legislative framework, including specific provisions, and review processes for medicinal products
- Understand the various aspects of shortages of medicines and the role the different stakeholders in the management and mitigation of these
- Critically evaluate the pharmacovigilance of a medicinal product
- Demonstrate competence in the management of lifecycle activities of a medicine
- Locate and navigate regulatory agencies' websites

### **Principles and practices of Health Technology Assessment (HTA)**

**– delivered by the Dept. of Pharmacology & Therapeutics, Trinity College Dublin, in association with the National Centre for Pharmaco-economics (NCPE) and the Health information and Quality Authority (HIQA)**

**Duration: 10 weeks (TBC)**

**1<sup>st</sup> face-to-face session: Week beginning Sept. 9th, 2019 (half-day)**

**2<sup>nd</sup> face-to-face session: Week beginning Oct. 14th, 2019 (half-day)**

**3<sup>rd</sup> face-to-face session: Week beginning Nov. 11th, 2019 (half-day)**

**Venue: TBC**

After completing the module on HTA principles and practices, participants will be able to:

- Understand why HTA and economic evaluation are important for health policy decisions
- Identify the main HTA agencies in Ireland and in Europe and understand their different approaches to evaluating medicine and health technologies
- Compare how the benefits of a medicine are assessed from the perspective of the regulator, HTA agency/payer, and patient
- Understand what type of information contributes to a better understanding of clinical benefit
- Understand methods for identifying and combining clinical efficacy data
- Understand the principles, practical application and importance of patient reported outcomes in developing the evidence for health technologies
- Outline the difference between quantitative and qualitative research and the role that research plays in HTA
- Understand the technology reimbursement process in Ireland
- Understand how patient interest groups can be involved in the HTA process

### **Applying the skills and knowledge**

The IPPOSI Patient education programme aims to encourage participants to apply the knowledge and skills acquired through the programme in three main areas according to their experience and aspirations:

- **Patient Representation:** IPPOSI Patient Members could actively engage in representing a patient perspective in the health innovation process by interacting with scientific committees, HTA agencies, regulatory bodies, industry, academia and other relevant stakeholders in Ireland and at the EU level.
- **Communication:** IPPOSI Patient Members could contribute to raising awareness on patient involvement in health innovation amongst their communities, including patients whose voices are seldom heard, and the lay public. Examples of activities include writing articles and press releases; organising press conferences; facilitating cooperation with the media; being a spokesperson on TV and radio programmes; utilising social networks and blogs.
- **Education/Training:** IPPOSI Patient Members could play the role of facilitators/trainers by engaging in activities supporting the dissemination of patient education and information programmes for other patient communities and the general public through their patient networks. Examples of activities include: providing training to patient advocates; leading workshops; running information sessions for people interested in participating in clinical trials.

## The Methodology

The 2019 patient education programme will start in mid-January 2019 and will finish in mid-November, 2019.

The teaching methodology of the training modules relies on a blended learning approach: e-learning and three face-to-face training sessions per module. The full training is provided in English. The major part of the teaching will be delivered via e-learning. In addition, candidates must commit to attending the three face-to-face training sessions per module that will take place in a number of Dublin City Centre venues.

It is expected that successful candidates commit 160 hours (TBC) for the e-learning and approximately 5 days (in total) for the face-to-face training sessions over the 10-month period of the complete programme.

## Equal Opportunities and Accessibility

IPPOSI is committed to equal opportunities and will endeavour to accommodate the specific needs of applicants with disabilities, medical conditions and family circumstances that may have an impact on day-to-day activities, to participate in and successfully complete the IPPOSI patient education programme, as far as is reasonably practicable.

To this end, IPPOSI will:

- Encourage applications from people with specific needs
- Judge applicants who disclose specific needs solely on the basis of the selection criteria described in the related section of this Guide
- Invite applicants with a specific need(s) to contact IPPOSI to discuss how their requirements can be accommodated
- Work towards the earliest possible assessment of needs and offer of reasonable solutions where possible
- Take steps to encourage participants with progressive conditions, or who develop specific needs during the patient education programme, to continue their participation

## Faculty and trainers

IPPOSI will ensure that the course will be delivered by experts of the specific areas from different backgrounds: patient organisations, academia, regulatory, HTA, etc.

## Exams and Certificate

The IPPOSI patient education programme will use various methods of assessment to consolidate learning and to strengthen the knowledge of participants. To achieve this, the assessment may take a number of forms such as:

- Knowledge checks (quizzes) at the end of each lesson (NOT recorded)
- Recorded multiple choice (MCQ) tests at the end of each module
- Exercises during the face-to-face sessions

Upon attaining a pass grade in each of the 3 modules, participants will be issued with a Certificate confirming their successful completion of the 2019 patient education programme.

## Cost

All successful candidates will receive a full scholarship to attend the patient education programme. Reasonable travel, accommodation and food expenses for the face-to-face sessions will be paid for by IPPOSI. Expenses will be paid upfront as far as possible. We will not provide support to arrange travel but will provide directions to the venues etc.

## Selection Criteria & Procedure

A number of criteria will be used for selecting the participants to the 2019 programme.

The following criteria are prerequisites that applicants are obliged to meet:

- 1) Commitment to complete the programme - Successful candidates are expected to complete all three modules in full, including completing the e-learning components and attending the nine face-to-face training sessions (3 per module).
- 2) On completion of the programme, a commitment to apply the skills and knowledge acquired to increase patient representation, communication or facilitate knowledge and education in others
- 3) Basic experience/knowledge of medicines research and development
- 4) Working knowledge of English
- 5) High-speed Internet connection

The following criteria will be weighted by the Selection Panel:

- 1) Individual motivation
- 2) Commitment to use and apply learning  
*(Successful candidates are expected to use knowledge and skills that they acquire)*
- 3) Experience related to the three module areas for applying the acquired knowledge/skills
- 4) County of residence in the Republic of Ireland  
*(We strive toward building knowledge and skills that can be applied in as many local/regional settings as possible in the Republic of Ireland).*
- 5) Disease area

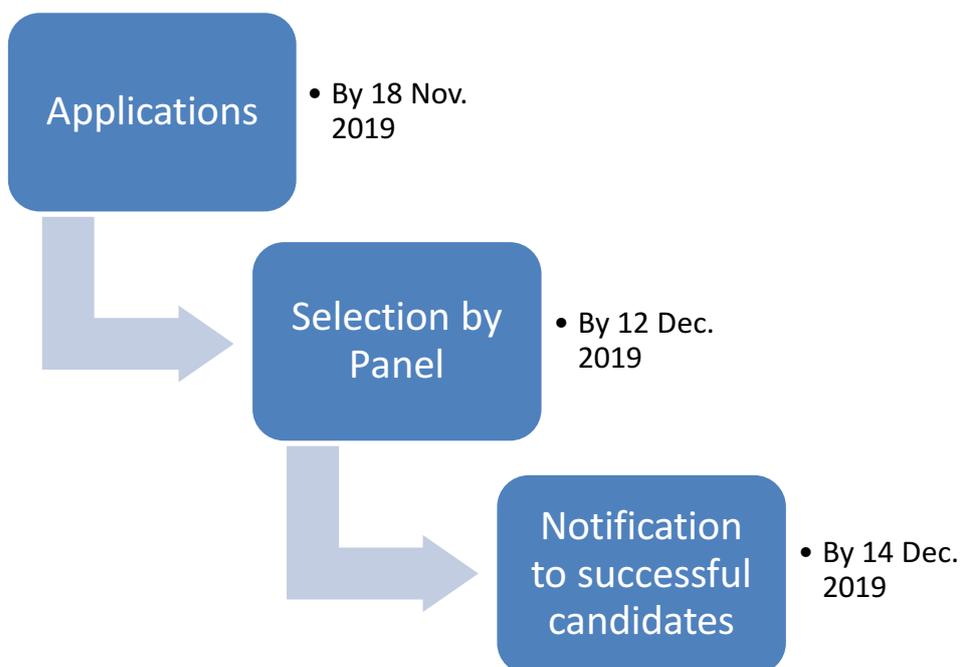
*(We strive at having patient advocates representing or working with different common or rare, chronic and/or lifelong, genetic or acquired, mental and physical diseases.)*

The selection of the participants is done via a transparent process. All applications received by the published deadline will be first reviewed for their accuracy and completeness. Those applications that pass initial screening will be evaluated for their content.

The final selection will be made by a Panel consisting of representatives from patient organisations, academia/science, healthcare providers and industry.

Applications will be assessed against the criteria listed above according to a transparent scoring system. Each member of the Selection Panel will first perform an independent assessment; all members will then convene in a meeting to agree on a final assessment and selection.

All applicants will receive notification by email to confirm if they have been successful or not **by 14<sup>th</sup> December 2018**. Successful candidates will receive guidelines for their participation to the programme.



## Data Protection

All personal data collected for the application process will be according to the Irish Data Protection Act 2018 and the EU General Data Protection Regulation (GDPR).

Applicants' data will only be used for the purposes of this procedure and will in no case be transmitted to any third party outside of IPPOSI staff. Any data provided will be treated in the strictest confidence and with high standards of security. All documents provided to IPPOSI during this application procedure will be kept in IPPOSI's files and will not be returned to applicants. Application documents will only be kept for as long as it is mandatory to fulfil the requirements of existing auditing/control procedures applicable to IPPOSI.

The Applicant is herewith informed by IPPOSI in detail on the type, scope, place of and reason for the collection, processing, and use of personal data necessary to process the application:

Personal data of the Applicant is used for the following purposes only:

- To ensure accurate communication with the Applicant by e-mail
- To perform the selection procedure for the education programme

Moreover,

- IPPOSI will not use Applicant's data to send unsolicited materials of any kind
- IPPOSI will not make Applicant's data available to third parties for marketing or promotional purposes
- The applicant has a right to access and ask to change or delete their personal data, which is kept by IPPOSI
- IPPOSI will always answer individual questions concerning the protection of personal data. Please send your questions or comments to [info@ipposi.ie](mailto:info@ipposi.ie)

By completing the application process, applicants expressly agrees to the collection, processing and use of personal data as described above. Applicants may opt out of receiving email communication from IPPOSI by indicating 'X' below. However, be advised that email is our primary channel of communication with applicants to the programme.

OPT OUT: \_\_\_\_\_

## Completing the Application Form

The information below will assist you in filling out the application form. The application has to be completed online by using the link provided in the section “How to apply” on the IPPOSI web page.

The information inserted is saved automatically. You can move from one page to the other by clicking

Prev

or

Next

If you close your navigator before final submission your information will be lost. The application will be submitted once you click the Tab Done . You will not be able to make changes after that.

Filling the application itself should take 20 minutes (without taking into account the motivation letter to be sent separately by email) (see PART 6 below)

### **PART 1 – GENERAL INFORMATION**

Please ensure that you indicate your email correctly, as all correspondence about the 2019 IPPOSI-led Patient Education Programme will be communicated via e-mail.

All personal data collected for the application process will be according to the Irish Data Protection Act 2018 and the EU General Data Protection Regulation (GDPR).

Applicants’ data will only be used for the purposes of this selection procedure and will in no case be transmitted to any third party outside of IPPOSI Staff. Any data provided will be treated in the strictest confidence and with high standards of security. All documents provided to IPPOSI during this selection procedure will be kept in IPPOSI’s files and will not be returned to applicants. Application documents will only be kept for as long as it is mandatory to fulfil the requirements of existing auditing/control procedures applicable to IPPOSI.

The Applicant is herewith informed by IPPOSI in detail on the type, scope, place of and reason for the collection, processing, and use of personal data necessary to process the application. Personal data of the Applicant is used for the following purposes only:

- To ensure accurate communication with the Applicant by e-mail
- To perform the selection procedure for the training programme

Moreover,

- IPPOSI will not use Applicant’s data to send unsolicited materials of any kind
- IPPOSI will not make Applicant’s data available to third parties for marketing or promotional purposes
- The Applicant has a right to access and ask to change or delete their personal data, which is kept by IPPOSI
- IPPOSI will always answer individual questions concerning the protection of personal data. Please send your questions or comments to [info@ipposi.ie](mailto:info@ipposi.ie).

The Applicant expressly agrees to the collection, processing and use of personal data as described above.

### **PART 2 – EXPERIENCE IN THE EDUCATION PROGRAMME TOPICS**

In this section you will have an opportunity to describe the experience / knowledge / understanding you have of the main topics of the 2019 IPPOSI Patient education programme.

For the employees and volunteers of patient organisations we are also interested in having some basic information about the organisation and their duties in the organisation.

### **PART 3 – AVAILABILITY FOR FACE-TO-FACE SESSIONS**

In addition to an extensive online e-learning, three face-to-face training sessions will take place in Dublin for each module (3 modules x 3 face-to-face sessions = 9 in total). Successful candidates are expected to complete in full the e-learning courses and all face-to-face training sessions. Please indicate your availability for the approximate dates for delivery of these workshops.

### **PART 4 – ADVOCACY EXPERIENCE**

The IPPOSI Patient Education Programme aims at enabling patient advocates to actively participate in the process of health innovation in different roles. In this section we would like to know about your interest, previous experience and skills in different areas where you may apply the knowledge provided by IPPOSI after the patient education programme. These areas are patient representation, communication and education/training. IPPOSI may provide additional training for each specific area, e.g., in communication.

The purpose for collecting this information is to help in building an IPPOSI ‘educated patient member’ database and to seek opportunities to involve you actively within IPPOSI activities.

### **PART 5 – LANGUAGE SKILLS, IT AND SPECIAL NEEDS**

All courses and teaching materials will be in English. Therefore, candidates must have working knowledge of English. In rating your language skills, please use the following criteria:

“native/advanced” – you have language proficiency equivalent to that of an educated native speaker. You are fluent in all of its features, including breadth of vocabulary and idiom on all levels and as normally pertinent to professional needs.

“good” – you can speak the language with sufficient structural accuracy and vocabulary to participate effectively in most conversations on practical, social, and professional topics. You rarely have to search for a word and unsubstantial errors virtually never interfere with understanding and rarely disturb the native speaker.

“intermediate” – your language skills satisfy routine social demands and limited work requirements. You can handle with confidence most basic social situations including introductions and casual conversations about current events, work, family, and autobiographical information, but you do not have thorough or confident control of the grammar and/or vocabulary.

“basic” – you can understand basic daily questions and speech, which allows for guides, such as slower speech or repetition, to aid understanding.

“none” – you do not understand the language at all.

The large majority of the programme will be delivered through e-learning modules. Applicants must therefore have regular access to a computer and high-speed Internet connection.

**Special Needs:** IPPOSI is committed to equal opportunities and will endeavour to accommodate the specific needs of applicants with disabilities, medical conditions and family circumstances that may have an impact on day-to-day activities, to participate in and successfully complete the IPPOSI patient education programme, as far as is reasonably practicable. Please describe in this part any specific needs you have; IPPOSI will contact you to have a clear assessment of needs and offer accommodations.

### **PART 6 – MOTIVATION LETTER**

In addition to submitting the application form, we ask you to submit a letter of motivation. Please describe your motivation, goals, objectives and expectations from attending the IPPOSI Patient education programme. We would like to see how your participation in this programme can contribute to improve health innovation in Ireland and further afield. In addition, please mention what will be

your unique contribution to the IPPOSI-led programme and to your patient community. You may want to highlight how your professional and/or educational experience fit with IPPOSI's objectives. Please ensure that your motivation letter is no longer than 1,000 words. Letters of motivation should be emailed to [info@ipposi.ie](mailto:info@ipposi.ie) by the application deadline, with the words 'Letter of motivation' in the subject line.

#### **PART 7 – COMMITMENT**

Taking part in the IPPOSI-led patient education programme will require a significant commitment to attend face-to-face training sessions, devote regularly extensive time and effort to e-learning, online mentoring and support. Please see the methodology description of the programme earlier in this document for detailed information of time investment required and timeframe.

We also expect applicants to commit to use the knowledge and skills acquired through this training in their different capacities as patient advocates or patient representatives.