



Irish EUPATI National Platform

2019 Action Plan

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IPPOSI, as coordinator of the Irish EUPATI National Platform (ENP) has updated the following ENP workplan for 2019. The purpose of this document is to act as a driver of discussions among Irish ENP members in the lead-up to the second Irish ENP meeting in June 2019.

Priority Areas for ENP members (in no order of preference)

- ENP members to review the governance and terms of reference of the Irish ENP
- ENP members to monitor the progress and future planning of the IPPOSI Patient Education Programme
- ENP members to map the interests of ENP patient members (online profiles + excel sheet)
- ENP members to map the existing patient involvement opportunities in Ireland (could inform a future PPI Directory project)
- ENP members to develop minimum standards for accepting patient involvement opportunities
- ENP members to organise a post-programme 'opportunities workshop' event after the 2019 IPPOSI programme graduation
- ENP members to explore how the ENP can raise awareness of the willingness to take up PPI opportunities among national health partners (research, regulators, industry, government)

'Involvement opportunities' for patient ENP members which IPPOSI can potentially create in 2019:

- 1 patient member to co-chair the EUPATI National Platform in Ireland
- Up to 2 members to join the IPPOSI Research & Advocacy Network
- Up to 2 members to join the IPPOSI Board Sub-Group on the 2019 annual theme 'Patient Data'
- Up to 2 members to assist with the planning of the Annual AGM & IPPOSI conference in October
- Up to 2 members to join the implementation working group for the IPPOSI Charter for Patient Involvement

Proposed 2019 Irish ENP Activities (as of Nov 10th, 2019)

Date	Event	Organiser	Opportunity Type, Location	Audience(s)	Irish ENP involved?	IPPOSI involved?
Jan 18 – Mar 30	Patient education programme module on Clinical Trials	UCD + IPPOSI	Peer mentor (speaking + online mentoring) + attendance at up to 3 workshops in UCD Belfield. Workshop dates: <ul style="list-style-type: none"> • Jan 18th • Mar 1st • Mar 29th 	25 patient students	Sarah McLoughlin	IPPOSI co-organising
Jan	Likely launch of application process for EUPATI Cohort 4 course – POSTPONED UNTIL SEPT 2019- SEE BELOW	EUPATI	Course to begin in March 2019	Pan-EU Call for applications	Dissemination of call among patient communities	Dissemination
Jan 31	EUPATI Cohort 3 Virtual Graduation (Webinar) – 5pm (Brussels time)	EUPATI	3 Irish EUPATI trainees graduating	Webinar	Gerard Eastwood, Olivia Shiel, Jacqui Browne graduating	No
Feb	eHealth Ireland Electronic Health record committees begin work	HSE, eHealth Ireland	Participation on eHealth Ireland EHR committees	HSE, eHealth Ireland committee members	Jacqui Browne, Sarah McLoughlin, Joan Jordan, Olivia Shiel, Richard Dalton, Sheila Fitzgerald	Derick Mitchell on eHealth Ireland advisory board

Feb 5	Irish ENP Meeting on Future of the ENP	Irish ENP / IPPOSI	ENP Meeting, St Vincents Hospital ERC	All ENP members	Yes	IPPOSI organising
Feb 28	Rare Disease Day Event, Chartered Accountants House, Pearse St. Dublin 2	IPPOSI, RDI, MRCG, NIRDP	Speaking opp Public awareness event, Dublin	Patients, Science, Industry, State Agencies,	Julie Power on organizing committee	IPPOSI co-organising
April (TBC)	Irish ENP Meeting - CANCELLED	Irish ENP / IPPOSI	ENP Meeting, (Webinar/F2F, TBC)	All ENP members	Yes	IPPOSI organising
May 15+16	NCPE Training Day on HTA	NCPE	Attendance at Training Day, St. James' Hospital, Dublin	Pharma Industry, patients	Olivia Shiel attended both days. IPPOSI are kindly offered 1 free place by the NCPE for patient member (normal cost = 500 euro).	No
Apr-June	2019 Patient education programme module on Medicines + Medical Device Regulation	HPRA + IPPOSI	Peer mentor (speaking + online mentoring) + Attendance at up to 3 workshops, HPRA offices: <ul style="list-style-type: none"> • Apr 26th • May 24th • July 5th 	25 patient students on programme	Joan Jordan	IPPOSI co-organising

May 1	Media Training for patients / Patient Organisations (15 reps)	IPPOSI	Attendance at Training day, Boston College, Dublin	Patient Members	15 trainees from ENP members + IPPOSI Ed. Programme students	Ken Rogan organising
May 13	Clinical Trials Event, Dublin	HRB-CRCI	Public awareness event, Mansion House, Dublin	Clinical Trial research community, policy, patients	Sarah McLoughlin, Derick Mitchell, Mark Moran on 2 panels.	Opportunities channeled through IPPOSI
May 20	EUPATI National Platform AGM (Copenhagen)	EUPATI + IPPOSI	Attendance at AGM event day, Copenhagen, Denmark	EUPATI Fellows + National Platforms	Irish ENP Reps invited to attend. Deirdre Hyland attended.	Derick Mitchell, Gemma Killeen, co-organising
Jun 12	Irish ENP Meeting (Webinar)	Irish ENP / IPPOSI	Webinar		Yes	IPPOSI organising
Sept-Nov	2019 Patient education programme module on Health Technology Assessment (HTA)	NCPE + TCD + HIQA + IPPOSI	Peer mentor (speaking + online mentoring) + Attendance at up to 3 workshops, HPRA offices (dates TBC) + Graduation Ceremony for 2019 programme	25 patient students on programme	Olivia Shiel	IPPOSI co-organising

Oct	Launch of application process for EUPATI Cohort 4 course	EUPATI	Course to begin in March 2019	Pan-EU Call for applications	Dissemination of call among patient communities	Dissemination
Oct 7th	AGM & IPPOSI conference	IPPOSI	Part of organising committee	150+ IPPOSI members	Jacqui Browne, Sheila Fitzgerald, Sarah McLoughlin form part of 'fireside chat'	IPPOSI organising
Nov 11th	2019 IPPOSI Patient Education programme graduation	IPPOSI			Wendy Costello presenting	IPPOSI organising
Nov 27th	Irish ENP Meeting (F2F)	Irish ENP / IPPOSI	ENP Meeting, (EU House)		Wendy Costello, Jacqui Browne presenting as part of agenda	IPPOSI co-organising

Opportunities advertised by IPPOSI in 2019 to patient members of ENP and/or individual patient members of IPPOSI.

No.	Date of action	Opportunity	Uptake by
1	Mar 5th	Helium Arts, the national children's arts and health organisation seeking parent representation, contribution to development of a Creative Health Hub Steering Group.	No uptake
2	Mar 27th	Royal Irish Academy Seminar - Emergency Medicine: managing the hospital bed crisis in Ireland'	Jackie Browne
3	Sept. 6 th	Semi-structured 30-minute interview as part of research into use of health apps, Irish Software Research Centre, University of Limerick	EOI by Stacey Grealis
4	Sept. 18-19	Attendance at the Open Forum on Patient Engagement Event, Brussels, Belgium	Wendy Costello

5	Oct. 7th	Patient 'Fireside Discussion' as part of upcoming IPPOSI Conference on Electronic Health Records (EHRs)	Sarah McLoughlin, Jacqui Browne, Sheila Fitzgerald
6	Early Oct. 2019	Speaking opportunity as part of UCC Pharmacy Student Module	No uptake
7	Oct 24th	Speaking opportunity as part of All Ireland Gerontological Nurses Association Annual Masterclass	No uptake
8	Nov. 6th	Patient representative on HIQA Advisory Group on a model for the collection, use and sharing of personal health information	Sheila Fitzgerald, Eileen O'Sullivan
9	Dec 3rd	Play:Decide Workshop as part of SCI:COM conference, AVIVA Stadium, Dublin 4	6 IPPOSI/ENP members: Sarah Mcloughlin, Jacqui Browne, Stacey Grealis, Alma O'Reilly, Anne Lawlor, Sean Heagney.
10	Dec 6th	Invite to consult with HPRA on establishment of Patient Forum	6 ENP members (TBC)
11	Dec 17 th (deadline)	Patient involvement in funding proposal to explore Sensory Enhancement strategies in Dysphagia (Swallowing Disorders)	EOI by John Dowling
12	Jan 2020 – June 2021	'Patient Educators' as part of MSc. in Digital Transformation, University of Limerick	TBC

Note: A number of 'opportunities' from individual researchers, conference organisers, stakeholders were received by the IPPOSI office during 2019. However, on pushback by IPPOSI regarding the 'meaningfulness' of these opportunities, these were not advertised to IPPOSI patient members.

The IPPOSI criteria whereby individual opportunities are weighed are as follows. If IPPOSI is approached to 'recruit/match make', internally, we take a step-wise approach:

Step 1: We ask ourselves the following questions:	Step 2: IPPOSI responds to the opportunity with a request for a 1-pager containing the following information:
<ul style="list-style-type: none"> • Is the initiative aligned with IPPOSI/EUPATI priorities? • Is the initiative at the 'generic' level, not the 'disease-specific' level? • Is the initiative at a sufficiently high level within an institution? (e.g. we don't tend to engage with student projects/short-term surveys etc.). 	<ul style="list-style-type: none"> • Background on the initiative - e.g. the 'why', anticipated benefit, etc.? • Expected benefit for the individual advocate • Expected time commitment involved • Details of any supports/honorarium that may be available • How the results of the initiative plan to be disseminated

<ul style="list-style-type: none">• Does the initiative appear to be well thought-out?• Is the initiative coming to IPPOSI with sufficient time to recruit?	
If we are satisfied that the initiative/opportunity is aligned with positive answers to these questions, we proceed to Step 2:	If we get a positive response to this request, we make an internal judgement call as to whether we canvass the Irish ENP patient members for their interest, and/or approach individual patients/patient organisation members who we are aware have a specific interest in the particular area.