



IPPOSI
PATIENTS SCIENCE & INDUSTRY

Priorities & Impacts

IPPOSI was established in 2005 by a visionary group of patient advocates, clinical researchers and medical industry participants who recognised that patients and the organisations that represent them should and must become legitimate partners in influencing health policy and driving innovations in health. Since its establishment, IPPOSI has become the go-to for members and policymakers to connect with disparate stakeholders in a complex health environment. The organisation has proved a greatly valued advice and information facility for members seeking to gain knowledge on recent initiatives and debates, or as a recognised vehicle to engage with Patient Organisations, Industry or Science members in their particular field.

The purpose of this Priorities and Impacts document is to outline our strategy for the next four years up to 2020. In this time, IPPOSI expects to play a pivotal role in bridging the gap between patients, science and industry and health policy and technology decision-makers both in Ireland and internationally. The Board of IPPOSI also recognise that the increasing emphasis on research and the role of patients within the healthcare environment in Ireland will continue to influence the key activities of IPPOSI.

IPPOSI's strategy has traditionally sought to bring a patient perspective to clinical research, to influence the policies that cover health research and access to health innovations, and to increase the awareness and understanding of IPPOSI's work. We have made progress in every one of these objectives; helping to establish policies such as Ireland's first National Plan for Rare Diseases; playing a part in the emerging focus on patient and public involvement (PPI) in research circles; as well as building the reputation of IPPOSI into that of a respected, trusted and effective member of the health community.

As we enter this new period, our strategic priorities are evolving to become more active advocates for improved, fairer access to health innovation, as well as driving meaningful patient involvement in health research and policy. We will also continue to build our profile as a patient-led platform that positively influences access to new health innovations for patients in Ireland.

Our strong international presence, reputation and network is well recognised from the leadership roles we play in pan-European research initiatives, which has resulted in IPPOSI being viewed as a unique model internationally.

Our strength is in our members and the positive, productive engagement and equal standing between all participants.

We look forward to our shared future and to you joining us on this journey.



Dr Tomás Carroll,
Chairperson,
IPPOSI Board



IPPOSI VISION:

Early, equitable access to Health Innovation for improved patient outcomes.

IPPOSI MISSION:

We are the collective voice of Patients, Science and Industry in enabling meaningful involvement in, and improved access to, Health Innovation

Strategic Priorities

The following IPPOSI strategic priorities have been agreed for the period of 2016-2020

Build IPPOSI brand and profile as a consensus-building group that influences access to Health Innovation*

Actively advocate[#] through our patient-led perspective for improved and equitable patient access to Health Innovation

Promote meaningful patient involvement in Health Research and Policy

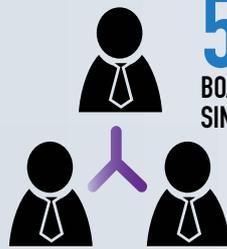
*Note 1: 'Health Innovation' includes new and existing Medicines, Interventions (both medical and non-medical), Medical Devices, E-Health Processes & Technologies, Information architecture/infrastructure (i.e. how health information is designed and used).

[#]Note 2: Advocacy is defined as the strategic use of IPPOSI representatives to increase awareness and understanding of issues related to patient access to, and involvement in health innovation across government, agency and regulatory spheres. IPPOSI advocacy activities will work in concert with other efforts carried out by patient organisations in the area of access to health innovations. Through a combination of high-level approaches, IPPOSI advocacy efforts will aim to help policy makers, individual agencies and regulators understand how an educated, empowered patient community can support each agency's mission and business needs.

IPPOSI 2010 – 2015



2500+
EVENT PARTICIPANTS



50
BOARD MEMBERS
SINCE 2010



2
CHAIRPERSONS



400+
TRAINING ATTENDEES



10
MAJOR MULTI-
STAKEHOLDER
MEETINGS



10
SUBMISSIONS
ON HEALTH
POLICY



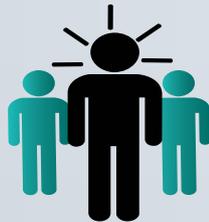
9
EXPERT
PATIENTS
TRAINED



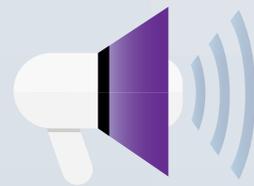
8
POLICY
GUIDANCE
DOCUMENTS



7
STRATEGIC
PARTNERSHIPS



6
HIGH-LEVEL ADVISORY
COMMITTEE
MEMBERSHIPS



5
FACILITATED
CONSULTATIONS



4
TRAINING
TOPICS



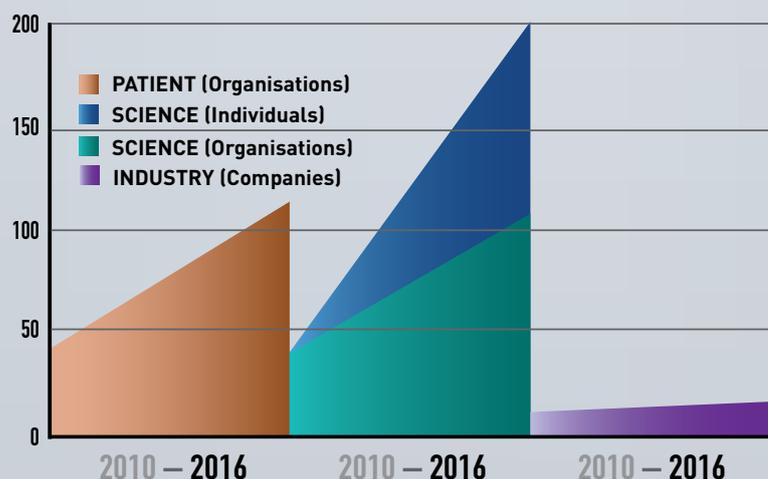
3
EUROPEAN
PROJECTS



2
CEOS



IPPOSI MEMBERS 2010 - 2016



Jim Breslin, Secretary General, Dept. of Health

"IPPOSI has made significant contributions towards the development of Irish health policy by harnessing a coherent voice that speaks for patients on a range of policy and innovation issues."

Dr. Graham Love, CEO, Health Research Board

"IPPOSI is a key player in 'Patient and Public Involvement' in Irish Health Research. Through its leadership role in Irish and European initiatives, IPPOSI is at the forefront of preparing patients for a partnership role in research while also working to create such partnership opportunities."

John McCormack, CEO, Irish Cancer Society

"IPPOSI does what most patient organisations cannot afford to do – it focuses on the issues that matter to all patients, irrespective of their health issue – rare or common."

Avril Daly, CEO, Retina International

"It's the critical voice of patients for health innovation. Since its beginning IPPOSI has strived to improve patient access to treatments, trials and decision-makers."

Philip Watt, CEO, Cystic Fibrosis Ireland

"IPPOSI has been a wonderful partner for the patient community at large, and for the rare disease community in particular. As a member of the Rare Disease Task Force, the Steering Group for the Rare Disease Plan, a co-author of the National Plan for Rare Diseases, and now as a member of the Implementation Committee, IPPOSI continues to fight for small groups and individuals who might otherwise not be heard."



Sinead Duffy, Bayer

"IPPOSI really is unique – it is an excellent model for bringing together the voices of patients, science and industry to focus on unmet medical needs."

Ava Battles, CEO, MS Ireland

"IPPOSI takes a strategic look at the future for all patients so that we don't have to. For the past few years IPPOSI has kept us informed and involved in areas like health information and connected health with exceptional events featuring world class speakers."

Prof. Orla Hardiman, Trinity College Dublin

"As a researcher, it is a very welcome change to encounter a new generation of patients who can collaborate in health research as partners. IPPOSI's focus on clinical research has made a significant contribution to this exciting change, and it will be a leader in Patient Involvement for years to come."

IMPACT 1 Rare Diseases

The landscape for people with rare diseases is a fast-changing one but remains extremely challenging in Ireland. Patients face daily difficulties in obtaining diagnoses, accessing specialists, and accessing innovative treatments that are unlikely to ever meet current criteria for cost-effectiveness.

Over the last decade IPPOSI has sought to influence this environment through a large number of collaborative activities, working with government and stakeholders, in particular with other patient-led networks such as the Genetic and Rare Disorders Organisation (GRDO) and the Medical Research Charities Group (MRCG). These efforts, combined with those from other groups, culminated in the publication of National Plan for Rare Diseases (2014) and the establishment of a National Rare Diseases Office (2015).



**John Devlin,
Deputy Chief Medical Officer, Dept. of Health**

"By providing a common platform, IPPOSI has helped many isolated voices in the rare disease community speak louder as one, in particular in the area of Orphan Drugs and Technologies."

The Irish Rare Disease Plan remains an exemplar on how patients and patient groups can be meaningfully involved in developing national health policy. IPPOSI was appointed by the Minister for Health as a member of the steering committee to develop the plan, drafting the chapter five on orphan drugs, and continues to be a member of the Oversight committee for plan implementation. We continue to press for speedier implementation of the plan recommendations. We welcome in particular the recent establishment of a HSE orphan drugs committee to bring forward appropriate decision criteria so that patients in Ireland can have access to new and innovative (or even established) orphan drugs and technologies in a timely manner.

The level of awareness and knowledge of rare diseases and the medical and social needs of the rare disease community remain at a critically low level. Since taking part in the very first International Rare Diseases Day in 2008 (and every subsequent one since then), IPPOSI is helping to highlight rare conditions in the minds of the public and has also regularly advocated for people with Rare Diseases at the Joint Oireachtas Committee on Health, with the Minister for Health and at the European level.

Working in collaboration with other stakeholders, together we can effect real and lasting change for all those affected by rare disorders living in Ireland. Those of us in the rare disease community need to give our full support to the individuals and organisations that continue to work tirelessly for much needed change in this area.

IMPACT 2 European Patient Academy on Therapeutic Innovation (EUPATI)

IPPOSI secured multi-annual (2012-2017) EU funding under the Innovative Medicines Initiative (IMI) as part of a 33-member consortium of patient organisations, academic institutions and pharmaceutical companies. The project is the European Patient's Academy (on Therapeutic Innovation) – EUPATI –designed to provide patients and the public with a wider and more in-depth understanding of the medicines development process.

As a leading member of EUPATI, IPPOSI has since led the establishment of multiple national platforms, or 'IPPOSI-like' organisations around Europe to inspire momentum on patient empowerment and education on medicines R&D at the national level. To date, 12 national platforms (Austria, Belgium, France, Germany, Italy, Ireland, Luxembourg, Malta, Poland, Spain, Switzerland, UK) have been established with a further six fledgling platforms (Portugal, Denmark, Netherlands, Slovakia, Serbia, Romania) in development.



Nicola Bedlington,
Executive Director, European Patients Forum

"A significant part of the EUPATI programme has been the establishment of over 12 National Platforms which seek to replicate the IPPOSI model around Europe. These platforms are bringing health partners together to identify the challenges, opportunities and educational supports for patients to become actively involved in medicines Research & Development."

In tandem, IPPOSI has lent support and expertise to the ongoing patient education programmes run by EUPATI, providing 9 Irish of the 100 European patient expert trainees, pictured above, who are all graduating at the end of 2016. IPPOSI is also taking part in an editorial board to turn the extensive course work of the expert training course into a 'toolkit' that is now available to patient advocates and the public online – www.eupati.eu

The IMI project is due to complete in early 2017 and IPPOSI will continue to support plans to sustain EUPATI into the foreseeable future. Indeed, IPPOSI is in a unique position to capitalize on the network and experiences established through five years of playing a leading role in EUPATI, and to bring these to the Irish health environment. Priorities include expansion of the Irish EUPATI platform, creating 'involvement opportunities' for Irish patients including the 9 Irish EUPATI fellows, as well as establishing a version of the EUPATI patient training course, tailored for Irish patients.

The availability of new treatments and technologies is a vital component of a good health service. IPPOSI and its member groups believe it is unacceptable for Irish patients to be denied access to health innovations such as new medicines, technologies, devices, processes, while patients elsewhere in Europe have access.

Access is a key focus for IPPOSI and we have led the debate in this area through a number of conferences, events & reports which have highlighted key challenges and proposed possible solutions in Ireland. As a result, strong working relationships have been established with a number of national and international stakeholders and state agencies in the area of Health Technology Assessments (HTA).



(L-R): John Church, Arthritis Ireland; Paula Guerin, AbbVie; Karen O’Keeffe, Pfizer; Derick Mitchell, IPPOSI

**Prof. Michael Barry,
Director, National Centre for Pharmacoeconomics**

“The NCPE has enjoyed a successful partnership with IPPOSI since 2011 to inform and educate patients on the Health Technology Assessment process, through actively communicating the concepts and principles that do (and do not!) inform reimbursement decisions in Ireland.”

Education on the HTA process can lead to greater acceptance of the important role this process plays in providing access to health innovations. Together with the National Centre for Pharmacoeconomics (NCPE), IPPOSI has facilitated an annual training day on HTA, educating patient members on the specific responsibilities they have and to encourage greater roles for patient representatives in the process.

In recent years challenges have emerged in access to new and often expensive treatments. While the process of HTA in Ireland is accepted by all as a transparent process (whether undertaken by the NCPE or HIQA), the decision-making process to reimburse needs clarity. Patients and the public need to know who the decision maker is and what the criteria for that decision includes, as the HTA is only one element.

IPPOSI has consistently highlighted orphan drugs as an example of where the HTA cannot be the only consideration. The formation of the Orphan Drugs Technology Review committee in 2016, as called for under Recommendation 30 of the National Rare Disease plan (2014-2018), is broadly welcomed by IPPOSI as a first step in this direction.

The contribution of patient registries to improvements in health policy, research and services remains a key area of focus for IPPOSI. Registries can help improve patient outcomes through providing decision-makers with information they need to make both policy and budget decisions as well as attracting clinical research where patients can get access to new, innovative treatments.

There remains a concern in Ireland that the full potential of Patient Registries in developing cost-effective and quality health services is undervalued. Together with the Medical Research Charities Group (MRCG), IPPOSI has called for an urgent national strategy to further develop and, in some cases, to sustain existing patient registries in Ireland as an invaluable tool for quality and cost effective patient services.



(L-R): Eibhlin Mulroe, formerly of IPPOSI; Jim Breslin, Department of Health; Richard Corbridge, HSE; Graham Love, HRB

**Prof. Eoin O'Brien,
Irish Skin Foundation**

"IPPOSI has provided a platform for patients to express their very positive views on the benefits of registries, and has provided a valuable source of advice and information in establishing the Irish Skin Foundation Registry."

In highlighting the importance of patient registries, IPPOSI has:

- Contributed to an evidence-based rationale for the development of a national strategy for Patient Registries in Ireland. A report "Towards a National Strategy for Patient Registries in Ireland - considerations for Government" findings were primarily drawn from a seminar jointly organised between IPPOSI and the MRCG, that brought together experts and key stakeholders in this area.
- Facilitated round-table sessions and seminars on patient registries with policy makers from the Dept. of Health with contributions from patients, regulators, scientists and industry.
- Assisted a number of patient organisations to design and establish patient registries through the IPPOSI members with most experience in this area.

The establishment of eHealth Ireland and the move towards electronic health records (EHRs) will lead to significant benefits but also consequences for existing and new patient registries. There needs to be a specific route whereby registries and their gatekeepers can, in a safe and secure environment, link with the national care records as part of the national roll-out of EHRs.

Health Information is a key focus for IPPOSI and we are leading the debate in this area through a number of round-table events & reports which have highlighted key challenges and proposed possible solutions in Ireland. As a result, strong working relationships have been established with the Department of Health, a number of state agencies and the office of the HSE Chief Information Officer.

IPPOSI ultimately wants to create a situation where Irish patients are the drivers of their own health data which will allow them to gain control of their health. Fundamental issues such as Individual Health Identifiers, "Meaningful Use of Patient Data" and the (much-delayed) Health Information and Patient Safety Bill, are of utmost relevance for IPPOSI member groups.



**Richard Corbridge,
HSE Chief Information Officer and CEO of eHealth Ireland**

"IPPOSI has shown a dedication and determination to drive person-centred healthcare in Ireland. Having the patient perspective at the centre of how eHealth develops in Ireland is critical to the delivery of a digital fabric and the assurance of releasing benefits to patients and clinicians alike".

The advent of electronic health records in Ireland has the power to improve both the efficiency and quality of care and research in Ireland while lessening the demands on the Irish healthcare system. Making health records available to patients, service users and carers (with appropriate patient consent) allied with continuous communication with the public (and key stakeholders) will be an essential part of building confidence and trust in the system to build electronic health records.

In order to address these (and other) health information-related issues, IPPOSI has:

- Brought health stakeholders together to debate and focus on eHealth solutions that emphasize the benefits of person-centred healthcare.
- Produced a number of policy-oriented outcome reports on the topics of Health Information and eHealth.
- Hosted consultations for the Privacy Impact Assessment on Individual Health Identifiers.
- In conjunction with the Medical Research Charities Group (MRCG) produced a summary on the Health Information Bill.
- Actively contributed as a member of the eHealth Ireland Committee, which oversees the implementation of the eHealth Ireland Strategy.

Since its inception, IPPOSI has brought a patient perspective to the improvement of clinical research in Ireland, with particular emphasis on promoting public awareness, encouraging patient and public involvement (PPI) and addressing barriers to developing a national clinical research infrastructure.

Promoting public awareness

Our clinical trials website (www.clinicaltrials.ie) and supporting leaflets continue to inform patients and the general public about taking part in clinical trials. The popular resource includes age-specific information for children taking part in clinical trials - work done in partnership with the National Children's Research Centre (NCRC) in Our Lady's Hospital for Children, Crumlin. IPPOSI regularly receives requests to use these materials in other countries with the booklets being translated into Spanish by Hospital Sant Joan de Déu, Barcelona.

IPPOSI commissioned and published research on public attitudes towards clinical research in Ireland. Key findings of this research include that 77% of people in Ireland agree that clinical research with the aim of developing new ways to treat many diseases is a good idea; 65% of Irish people would be willing to share personal medical information for medical research if it is done in a confidential manner.

What is a clinical trial?

A clinical trial is a research study in human subjects with the aim of answering specific questions about a new medical treatment (vaccines, new therapies or new ways of using known treatments). Clinical trials (also called medical research and research studies) are used to determine whether new drugs or treatments are both safe and effective. Clinical trials are conducted in phases. The trials at each phase have a different purpose and each phase looks at different areas (e.g. toxicity, dose finding etc).

Is clinical research the same thing?

Clinical trials are generally research programmes for drug development, other types of clinical research may include medical device investigations, blood sampling, questionnaires and evaluating health care provision.

Who is allowed to set up a clinical trial?

Clinical trials are designed by groups of medical and other specialists. The trial design is usually based on a thorough analysis of existing research, and a realisation that certain questions about treatment or symptom control need to be answered. The trial design is discussed with medical staff, nurses, patients, statistical experts and support staff, as well as representatives from drug companies, to draw up the best possible trial design. The design for the study is known as the 'protocol'.

Prof. Colm O'Morain, Trinity College Dublin

"Clinical research would be impossible without the active involvement of patients. By harnessing the collective experience of patients, science and industry, IPPOSI is a key driver in Ireland for improved access and increased quality of clinical research in Ireland."

Encouraging patient and public involvement (PPI)

- IPPOSI hosts an annual clinical research training session, entitled 'Clinical Research for non-Clinical Researchers' to educate members on the concepts of clinical research in Ireland.
- IPPOSI is working closely with Clinical Research Coordination Ireland (HRB-CRCI) to focus attention on PPI in clinical trials. A working group from the emerging clinical research infrastructure in Ireland is working towards this objective.
- Through the Irish EUPATI National platform, IPPOSI is encouraging the development of PPI opportunities for Irish patients and their communities in the clinical research environment.

Improving barriers

- IPPOSI has co-hosted a number of major policy-focused summits and conferences on the barriers, challenges and possible solutions for the clinical research infrastructure in Ireland.
- IPPOSI has contributed to the development of biobanking activities in Ireland and Europe through our close links with the pan-European biobanking infrastructure – BBMRI-ERIC.



IPPOSI

IRISH PLATFORM FOR PATIENTS' ORGANISATIONS, SCIENCE & INDUSTRY

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