



Patients re-imagining healthcare in Ireland

COVID-19 presents an unprecedented challenge to public health for our modern society. But as the immediate emergency subsides, it also offers an unprecedented opportunity. We now have an opportunity to re-imagine – re-imagine how we design, deliver, inform, and evaluate healthcare in the future. The opportunity to embrace new solutions to old problems, the opportunity to involve and inspire.

Patients want to be, and should be, an integral partner in this re-imagining.

A CORNERSTONE OF ANY RE-IMAGINED HEALTH SYSTEM MUST BE A FRAMEWORK TO FACILITATE MEANINGFUL AND SUSTAINED PUBLIC AND PATIENT INVOLVEMENT ACROSS ALL ELEMENTS OF OUR HEALTH SECTOR (SERVICES, POLICY, RESEARCH, GOVERNANCE).

Re-imaginings are not easy. There are many component parts which need to slot smoothly, flexibly, and efficiently into each other to allow the machinery of the health system to deliver timely and equitable care for all our citizens. There is the temptation to leave the re-imagining to health leaders and clinicians. But this is the old way. This is not the health future we, as patients, imagine. We propose a new, stronger, equal partnership between health leaders, clinicians, and patients

PATIENTS NEED TO BE BROUGHT INTO THE DIALOGUE AS RESPECTED AND EQUAL PARTNERS. WE NEED TO BE ABLE TO HAVE A SAY IN CHARTING THE COURSE, IN DEFINING THE PARAMETERS, IN PROPOSING THE POTENTIAL SOLUTIONS.

But we will be honest. We do not know precisely what this framework should look like, but we have some ideas, we can share some good examples, and we can identify person-centred aspects we aspire to adopt. At the moment, we are not overly preoccupied by what the destination looks like (this focus comes later). What matters for us is that we (patients, managers, clinicians, payers) get on the path together and improve the collective journey.

ENGAGING PATIENTS AS PARTNERS ALLOWS FOR A MUTUALLY BENEFICIAL, TWO-WAY RELATIONSHIP TO BE ESTABLISHED. IT CONVEYS CLEAR RIGHTS AND RESPONSIBILITIES ON ALL PARTIES – PATIENT AND PROVIDER. PATIENTS ARE NO LONGER ON THE OUTSIDE LOOKING IN. PATIENTS ARE ON THE INSIDE HELPING; PROBLEM-SOLVING.

Fundamentally, health leaders, clinicians and patients all share the same goal of achieving better health outcomes. We all want to be proud of, and confident in, the care provided and received. We all aspire to a coordinated, integrated, and patient-centred system of care. We need to develop a health system and culture which embraces person-centred coordinated care, and the belief that involving patients is part of the solution.

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A framework will set in motion and drive forward the cultural change and strategic commitment needed to increase and improve the involvement of the public and patients in future healthcare. **At policy and organisational levels**, it will incorporate patients into governance structures, it will create advisory patient bodies, it will promote co-management of clinical programmes, it will ensure the necessary education and supports are provided, and it will support co-production of research projects. **At a direct care level**, it will capture the patient experience, it will promote shared decision making between clinician and patient, it will see patients help other patients improve their self-care.

The opportunities are endless. The prospect is both daunting and exciting. We must be brave. We must plan for better. IPPOSI, as the voice of 100+ patient organisations (and many more individual patient advocates), stands ready to engage and channel the many patient voices we represent, to partner constructively with other stakeholders, and to co-design a framework for public and patient involvement in health – our COVID-19 legacy to the next generation of Irish patients.

This vision is supported by IPPOSI patient, science, and industry representatives. It has been reviewed and endorsed by:

The IPPOSI Board: representatives from patient, science and industry elected to provide strategic advice and governance

- Ava Battles (Chair), MS Ireland
- Neil Johnson, CROI
- David McMahan, Irish Skin Foundation
- Sarah O'Connor, Asthma Society Ireland
- Anne-Marie O'Dowd, Cystinosis Ireland
- Grainne O'Leary, Arthritis Ireland
- Julie Power, Vasculitis Ireland Awareness
- Kevin Whelan, Fighting Blindness
- Orla Hardiman, Trinity College Dublin
- Anne-Marie Healy, Trinity College Dublin
- Louise Hopper, Dublin City University
- Jason Last, University College Dublin
- Gaye Stephens, Trinity College Dublin
- Nuala Carey Abbie
- Eleanor Hannon, Biomarin
- Conchuir MacGloinn, Roche
- Susanne O'Reilly, Novartis
- Brid Seoighe, Janssen

The IPPOSI Policy Advisory Committee: representatives from patient, science and industry selected for their expertise in health policy

- Tomás Carroll, Alpha-1 Foundation
- John Dowling, Men Against Cancer
- Aoife Kirwan, MS Ireland
- Rachel Morrogh, Irish Cancer Society
- John McCormack, Policy Advisory Committee member
- Julie Power, Vasculitis Ireland Awareness
- Gaye Stephens, Trinity College Dublin
- Gianpiero Cavalleri, RCSI
- Jon Salsberg, University of Limerick
- Clare Harney, IMSTA
- Carmel Mulroy, Bayer
- Fred Doherty, Sanofi
- Paula Guerin, independent consultant (industry representative)

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