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IPPOSI submission to DHFERIS public consultation on Scientific Advice

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Irish Platform for Patient Organisations, Science & Industry - IPPOSI

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Question 1

How should science advice fit into the overall policy process, including the broad reform agenda (such as the generation of evidence for policy, and strengthening policy development and foresight in the public service)?

IPPOSI Response to Q1

A FULL TIME, CROSS-DEPARTMENTAL, WELL SUPPORTED ROLE

The position of Chief Scientific Advisor (CSA) to the Government needs to be a dedicated full-time role, which is held independently of all funding agencies, and which is supported by an office that is adequately resourced (both human and financial) to fulfil its duties and responsibilities. The CSA should transcend government departments (given its multi-disciplinary work) and it should ideally report to the office of the Taoiseach to ensure visibility for this cross-departmental role. The CSA should be recruited through the public appointments process, and the process should be transparent and merit-based.

AN ACTION PLAN FOR EMBEDDING SCIENTIFIC ADVICE

The CSA should be tasked with developing a national action plan for putting science advice at the heart of policy development so that it is clear to all how science advice fits into the overall policy process and how this is done in a standardised way and on an ongoing basis. This action plan should help us live the vision detailed in *Impact 2030*. A review of the existing policies, processes, and practices for incorporating science advice should inform this action planning. The action plan should include a focus on increasing the scientific and technological literacy of those already operating within the system, with a focus on decision-makers at the highest level of government.

AN INCLUSIVE PRIORITIZATION PROCESS

The CSA should lead the public identification of priority areas of scientific or technological interest. These priorities should be agreed in consultation with a range of stakeholders including the proposed R&I Advisory Forum under *Impact 2030*.

Action plans should be elaborated to ensure that science advice is at the heart of our policy responses in these priority areas. The CSA should focus on creating opportunities for cross-departmental collaboration and dialogue around these priority areas. The CSA should coordinate the work of a network of scientific advisors situated in government departments and in other state agencies, and responsibility for advancing evidence-based content in these priority areas should be shared across the individuals involved in this network.

The CSA should receive advice from a multi-disciplinary panel of experts drawn from national bodies, including the RIA, SFI research centres, IBEC, and IUA. The CSA should also foster links with private enterprise and industry to be able to exert influence across the science and technology sector. The CSA should lead on creating a science and technology sector which offers more opportunities for underrepresented groups to get involved in, or indeed start careers in, this sector.

The CSA should also identify opportunities and create mechanisms for including public, lay, voices - to collect so-called 'lived experience' knowledge and evidence. The involvement and participation of public or lay voices should be done on the basis of a transparent and open call for expressions of interest, and based on a pre-agreed criteria for the types of voices needed, and for the role they will play. Public or lay voices should be adequately and appropriately supported in their roles, including remuneration for the time given for their involvement. Public or lay voices should include a combination of individuals and civil society representatives, to ensure that these voices are connected back to a broader community.

OVERSIGHT OF FUNDING AGENCIES

The CSA should objectively report to the government on the performance of funding agencies and provide independent oversight of the existing ecosystem to avoid duplication and unnecessary overlap between agencies. The CSA should focus on promoting a shared scientific and technological vision among agencies, and on encouraging the sharing of information, equipment and facilities.

The CSA should ensure that one agency takes responsibility for funding projects when an effective project funded by another agency ends, for example, SFI outputs feeding into Enterprise Ireland commercialisation.

Question 2

What examples and experience do you have where advice has been effectively sourced and applied?

IPPOSI Response to Q2

IPPOSI's experience over the past 15 years has been in the health sector – both national and international. During COVID, the role played by the Chief Medical Officer and his team and the role played by NIAC are good examples of how the government has effectively sourced and applied advice. The government were able to use this advice to inform its decision, and the public were able to make a clear distinction between the advice received from public health experts and the action taken by the government (whose decision were based on scientific advice plus other types of advice, economic etc).

Question 3

What examples and experience do you have where advice could be more effectively sourced and applied?

IPPOSI Response to Q3

IPPOSI's experience over the past 15 years has been in the health sector – both national and international. Much of the advice needed to support a better health future – in terms of service improvement, policy development, research, and innovation – could be more effectively sourced if the necessary infrastructure and investment were in place to support the standardised collection of health data and its appropriate secondary use.

Advice can only be provided where the data is available, and the health data available in Ireland at the moment is poor – incomplete, fragmented, siloed, and not interoperable. We need to invest in a national electronic health record to collect digital health information for us that can be appropriately and securely shared and used to support better science and technological research. We need a patient portal so that individuals can engage with their own health information and better understand the value of health information, including its aggregation for the delivery of evidence-based public policy options. Internationally, we are a laggard in this space, but can 'catch up' with the right approach and application.

Question 4

How could any existing sources be better mobilised?

IPPOSI Response to Q4

The CSA should aim to:

- foster more inclusive, multi-disciplinary research approaches that attract 'non-traditional' disciplines, include new voices and communities, and focus on leveraging Irish cultural strengths in the arts and humanities.
- promote a more cohesive multi-departmental, multi-agency approach to scientific R&D, in consultation with all stakeholders to optimise the funding landscape and avoid unnecessary barriers and duplication.
- support engaged research models such as co-production, where researchers work in partnership with a range of public research stakeholders, including public or professional service users, policy makers, civil and civic society organisations (CSOs) and actors who identify a problem and have the authority or ability to implement the research recommendations.

Question 5

What kind of individual skills and competencies do science advisors, scientists, and government officials need to develop to effectively populate or engage with science advisory structures?

IPPOSI Response to Q5

The CSA should have a track record of transformational leadership and change. The task ahead is a significant one, and there are difficult decisions which need to be taken to restructure the landscape and to start to 'do business' in a different way.

The CSA should have a deep understanding of and commitment to engaging with civil society and public voices to identify issues requiring prioritisation for scientific advice, to review the body of evidence feeding into scientific review, and to communicate the results of scientific review to citizens.

The CSA should have excellent communication skills which enable him/her to adapt their interventions to a scientific or public audience and expertise in building and maintaining wide ranging relationships with diverse stakeholders.

The CSA should have a national and international reputation and presence, together with established network of contacts both here and abroad, including within key fora of relevance to Ireland.

Question 6

How can we make sure that citizen involvement, public trust and experience-based knowledge is included in any science advisory structure?

IPPOSI Response to Q6

The CSA should include the promotion of public (and in the case of health, patient) involvement in structures relating to research strategy, policy and oversight. This requires more dedicated funding and resources in areas such as public discourse/dialogue, citizen jury / assembly-type approaches, science communication and engagement of minority groups.

As a general principle, we must only communicate with the public in a way which is understandable for the public – and this holds especially true for scientific advice which, by its nature, can be complex and intimidating for many. We must try to reach members of the public through as many diverse channels as possible to communicate with as wide a cross-section of the population as possible. The goal is to start a dialogue, rather than maintain a monologue, and we should consider doing this by adopting a suite of participatory

approaches – including citizens’ assembly and citizens’ jury style tools – which can get individuals actively involved in discussing a range of key issues with both experts and peers in a sustained and dynamic way.

This should be complimented by a remit for the CSA office to lead the charge on re-igniting national investments in a Science Gallery/Science Museum physical space where public engagement, science communication and dialogue can take place ‘under one roof’ and future generations of Irish scientists can be inspired to visit and participate in.

Question 7

How can the Irish system be better-connected to EU and EU-27 science advice processes?

IPPOSI Response to Q7

The CSA should oversee the Irish response to the European research agenda – they should have a clear overview of the different initiatives being pursued by the different funding agencies. The CSA should ensure that any gaps in Irish involvement are plugged, and that Irish organisations are linked in with key European projects, and are actively encouraged and supported to take up leadership roles within projects which align with our priority areas.

Genomics is an example of where Ireland could be better connected with European science advice. The CSA should engage the Department for Further and Higher Education, Research, Innovation and Science and the Department of Health to jointly develop an Irish Public Genome Project which could allow for ‘trusted’ public-private partnership and would protect genomic data for the benefit of the Irish public. Ireland should seek to align our national strategy and programme with European initiatives, including the 1M+Genomes project, and we should establish a Irish Mirror Group to learn from and share information with our European Member State counterparts engaged around this issue.

Annex I – Who is IPPOSI?

The Irish Platform for Patient Organisations, Science and Industry (IPPOSI) – is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of health innovation.

To that end we hold meetings, workshops and training days that promote this objective, whether it is in the area of rare diseases, clinical trials, Health Technology Assessment, health information, digital health – or any other relevant topic that will promote patient understanding, and patient involvement in the treatment and decision-making processes that affect them in Ireland and Europe.

Through more than 15 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 health innovation and education processes. 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.

IPPOSI Board - <https://www.ipposi.ie/about-us/board>

David McMahon, *Irish Skin Foundation (Chairperson)*,
Sarah O'Connor, *Asthma Society of Ireland (Vice-Chairperson)*
Julie Power, *Vasculitis Ireland Awareness*
Joan Johnston, *COPD Support Ireland*
Gráinne O'Leary, *Arthritis Ireland*
Rachel Morrough, *Irish Cancer Society*
Pascal Derrien, *Migraine Association of Ireland*
Prof Jason Last, *University College Dublin*
Prof Gaye Stephens, *Trinity College Dublin*
Prof Gianpiero Cavalleri, *Royal College of Surgeons, Ireland*
Dr Louise Hopper, *Dublin City University*
Dr Patrick Harrison, *University College Cork*
Hugh Nolan, *Dundalk Institute of Technology*
Eleanor Hannon, *Biomarin*
Conchúir MacGloinn, *Roche*
Harriet Doig, *MSD*
Ruth McIver, *Novartis*
Ita McCarron, *GSK*
Maureen Mason, *PTC Therapeutics*

IPPOSI Membership - <http://www.ipposi.ie/about-us/membership/>

105 Patient Organisations
126 Patient Advocates
244 Academic Scientists
23 Healthcare Industry Companies