

WE CALL FOR PATIENTS, VULNERABLE PERSONS AND FAMILY CARERS TO BE PLACED AMONG THOSE IN HIGHEST PRIORITY FOR VACCINATION, AND FOR A STRATEGIC PLANNING PROCESS WHICH RESPECTS INVOLVEMENT, EVIDENCE AND TRANSPARENCY.

08 December 2020

A joint letter from patient organisation and vulnerable group representatives to Government, High-Level Task Force, NPHET and HSE representatives charged with developing a national immunisation plan for a COVID vaccine

We represent 15 patient and vulnerable group organisations. Our members include some of the most vulnerable people in the country. As Ireland develops its national COVID-19 immunisation strategy and implementation plan, **we call on the Taoiseach, the High-Level Task Force, NPHET and the HSE to take steps to ensure an inclusive, evidence-based, and transparent process; and to prioritise patients, vulnerable persons and family carers in the highest priority category for vaccination.**

We call on the Task Force, NPHET and the HSE to:

- ensure public and patient involvement in decision-making; and we ask for the immediate appointment of two public representatives to the Task Force, the reinstatement of the NPHET Vulnerable Persons Sub-Group, and the initiation of *early* consultation with the HSE National Patients' Forum
- urgently engage patient organisation and vulnerable group leaders in an open and ongoing dialogue
- carefully review those at greatest risk of morbidity and mortality; and acknowledge the special situation of patients, vulnerable persons, and their carers
- prioritise human wellbeing; and alongside frontline healthcare workers and nursing home residents and their carers, prioritise people with health conditions and their carers who risk severe disease or death should they contract the virus
- ensure that there is a full and public account of Task Force, NPHET and HSE decision-making throughout this strategic planning process, which should include public consultation.



INVOLVEMENT

The experience of NPHET demonstrated the need for, and value of, including vulnerable persons representatives within decision-making structures. Following the example set by Australian, American and British Governments, **we call on the High-Level Task Force to build upon this practice of public involvement and immediately appoint two public representatives to the list of Task Force members.** These representatives should be capable of ensuring that the voices of patients and vulnerable persons are adequately heard. This informal alliance of patient organisation and vulnerable group representatives are happy to work with the Government to identify these representatives.

The addition of two public representatives to the High-Level Task Force will demonstrate the government's willingness to dispel public fears of a 'closed shop'. This step alone will not be sufficient to capture the full breadth of expertise available to the Task Force from within the patient organisation and vulnerable groups community. **We ask that the Task Force urgently engage patient organisation and vulnerable group leaders in an ongoing dialogue,** both to inform strategic planning, to manage expectations within these communities, and to propose solutions to public information campaigning and vaccine uptake challenges. This informal alliance of patient organisation and vulnerable group representatives would welcome the opportunity to engage with the High-Level Task Force in a more in-depth conversation over the coming days and weeks and we remain available to do so.

As the Task Force is supported in its activities by several other entities, we also call on NPHET to reinstate its Vulnerable Persons Sub-Group (and any other relevant Sub-Groups) to contribute to NPHET recommendations around this issue. Similarly, the appropriate offices in the HSE should ensure that public and patient voices are incorporated into any decision-making taking place in this area.

We strongly believe that these steps will benefit the process and ensure Ireland takes a person-centred approach to public health.

EVIDENCE

The experience of navigating public health measures during this pandemic indicates that the public is generally able to accept most decisions if they are backed up and reinforced by evidence. The decision around the roll-out of COVID-19 vaccines are likely to be no different. **We call on the High Level Task Force, NPHET and the HSE to carefully review those at greatest risk of morbidity and mortality from COVID-19,** recognising as other Governments have done, that many of those cocooning, shielding or self-isolating do not appear in research studies due to the status of their confinement.

We also call on the Task Force, NPHET and the HSE to acknowledge the special situation of patients and vulnerable persons, and family carers, many of whom have long recognised that without a vaccine their lives will not return to normal, while also acknowledging that they can never participate in the 'new normal'. Patients and vulnerable persons have distanced themselves from their families and loved ones to protect their physical health; patients have had to measure up the risk of attending appointments and availing of procedures against the risk of contracting the virus; and all have witnessed a serious deterioration in their quality of life. This is a reality that few can identify with. A vaccine offers an end to this cycle of loneliness and anguish.

There will be many competing demands to meet, but **we call on the Task Force, NPHE and the HSE to prioritise human wellbeing, and to prioritise, in a first category alongside frontline healthcare workers and nursing home residents and their carers:**

- **people with health conditions who risk severe disease or death should they contract the virus; and**
- **carers of those with health conditions who risk severe disease or death who are ineligible to receive the vaccine because of age or an underlying health condition.**

We include some prioritisation approaches adopted in other jurisdictions in annex to this letter.

TRANSPARENCY

The decisions made by the High Level Task Force, NPHE and the HSE will have a profound effect on the lives of every single resident in Ireland, but none more so, than those in our society who have had no choice but to cocoon, shield or self-isolate since the start of this pandemic almost ten months ago. **We call on the Task Force, NPHE and the HSE to ensure that there is a full and public account of decision-making throughout its strategic planning process**, including advance notification of meetings and agenda items, and timely summaries of meeting minutes and decisions. The final recommendations of the Task Force should not simply be published as a fait accompli - there must be public debate. The American and French Governments have opened their draft recommendation for public consultation. While we recognise time constraints and conflicting priorities at this time of year, **we call on the Task Force to consider some element of public consultation** to ensure that the Government has a greater understanding of public values and beliefs.

We the undersigned are united in calling for immediate action to be taken to prioritise the vaccination of patients and vulnerable persons at high risk of severe disease or death as a result of contracting COVID. Human wellbeing must be foremost in our decision making, and those whose physical and mental health has suffered most during this difficult time must have relief at the earliest possible stage.

- Seán Moynihan, Chief Executive, **ALONE**
- Geraldine Kelly, Chief Executive, **Alpha 1 Foundation**
- Emily Blennerhassett, Interim Chief Executive, **Asthma Society of Ireland**
- Neil Johnson, Chief Executive, **Croi, West of Ireland Cardiac & Stroke Foundation**
- Joan Johnston, National Coordinator, **COPD Ireland**
- Kieran O'Leary, Chief Executive, **Diabetes Ireland**
- John Dolan, Chief Executive, **Disability Federation of Ireland**
- John Dunne, Chief Executive, **Family Carers Ireland**
- Derick Mitchell, Chief Executive, **IPPOSI**
- Rachel Morrogh, Director of Advocacy and External Affairs, **Irish Cancer Society**
- Chris Macey, Head of Advocacy, **Irish Heart Foundation**
- Martin Rogan, Chief Executive, **Mental Health Ireland**
- Magdalen Rogers, Executive Director, **Neurological Alliance of Ireland**
- Vicky McGrath, Chief Executive, **Rare Diseases Ireland**
- Sarah Lennon, Executive Director, **Sage Advocacy**