

**#IPPOSI's submission to the
Joint Committee on Disability
Matters on behalf of 16
patient, carer, and medically
vulnerable group
organisations**

26 January 2021

Thank you for this opportunity to make a submission to the Joint Committee on Disability Matters.

We are a coalition of 16 patient, carer, and medically vulnerable group organisations coordinated by IPPOSI, the Irish Platform for Patient Organisations, Science and Industry. We are calling for people with disabilities and chronic and/or rare condition(s) to be given greater priority for COVID-19 vaccination and for patient organisation leaders and representatives to be included in future policy discussions and decision-making processes related to the national immunization plan. We sent a joint letter to the Chair of the High Level Task Force on 08 December 2020¹.

Below we share our most pressing concerns, and we urge you to join us in recommending:

- a review of the current allocation of priority for vaccination and a proposal to prioritise persons with chronic and/or rare condition(s) of all ages and at high-risk from COVID-19 alongside the planned vaccination of persons aged 70 and over;
- a review of how frontline healthcare workers have been prioritised within allocation group (frontline healthcare workers) and a proposal to prioritise all frontline health and social care workers, including all those working with people with disabilities and chronic and/or rare conditions;
- a renewed focus on researching the ongoing risk factors for severe disease and/or death from COVID-19 for patients with chronic and/or rare condition(s), taking into account that some patient communities may be largely unrepresented in research or in official statistics due to their current cocooning status;
- a detailed public timeline for the vaccination of each priority group, together with clear public health information on how persons with high risk chronic and/or rare condition(s) will be identified and called for vaccination;
an expert opinion on vaccine selection and vaccine dose spacing for persons with high risk chronic and/or rare condition(s), making this advice publicly available;
a clarification on the position of family carers of persons with high risk chronic and/or rare condition(s) within the vaccination allocation plan;
a review into the operational status of the NPHEC Sub-Group for Vulnerable Persons, alongside the immediate appointment of patient representatives to key policy and decision-making bodies tasked with the detailed implementation of the national immunisation plan, including to the High-Level Task Force;
- a mechanism to establish regular, two-way communication between the Department of Health and patient organisation leaders, with the mutually-beneficial purpose of ensuring that patient issues and concerns are directly addressed and that public health information is tailored to patient community requirements.

Our recommendations are derived from a combination of our own research into patient perspectives, and international good practice, together with our observations of national developments and updates.

¹ <https://www.ipposi.ie/2020/12/07/patients-voice-covid-19-prioritisation/>

The prioritisation for vaccination of persons with chronic and/or rare condition(s) due to the high risk of severe disease or death due to COVID-19

The COVID-19 pandemic has affected us all, but it has not affected us all equally. Persons with chronic and/or rare conditions, and their families and carers, have borne a tremendous burden since the very early days of this public health emergency in March 2020. Many have been forced to cocoon indefinitely, to give up their employment, to withdraw their children from school, to isolate themselves from close family members, to cancel important medical appointments and procedures. Other people with disabilities and chronic conditions have had to continually risk exposure to the virus in order to access essential services including personal assistance and home support, therapy and medical appointments. They are not living, they are not able to participate in the 'new normal'; they are isolated, excluded, simply surviving. Only a vaccine offers these persons with chronic and/or rare conditions the hope of a better quality of life.

We believe the current age-based approach to vaccination priority somewhat overlooks the plight of persons with chronic and/or rare condition(s). The Government claim that *"Those who have been prioritised for vaccination are the most likely to die, or those who have shouldered the heaviest burden in the pandemic so far"*² while laudable in theory, seems not to play out in practice. Chronic and rare conditions do not only affect older age groups. Many people under 65 live with these conditions, yet they are only seventh in line for vaccination according to the Government's national immunisation plan approved on 15 December 2020.

The process for arriving at this decision, the inclusion of an ambiguous sixth category of 'key worker', and the poor delineation between patient-facing and non-patient facing healthcare professionals during implementation (second and fourth priority categories), have been hard to explain to our patient members. A recent IPPOSI survey with over 550 responses assessing the fairness of the current priority allocation groups reveals,

Just over 60% (336) described the priority for vaccination as 'not fair', with a further 29% (161) suggesting it was 'somewhat fair'. Only 5% (30) believed it to be 'very fair'.

The perception of unfairness may result from the largely age-based approach to vaccination priority adopted in Ireland, which when imposed uniformly is somewhat crude in its execution and fails to consider the nuanced impact of COVID across our society – both young and old. When we look to other jurisdictions, we can see that other examinations of risk and burden yielded different results:

- **In the UK**, the Joint Committee on Vaccination and Immunisation (JCVI) has assessed the overall risk of mortality for clinically extremely vulnerable younger adults to be roughly the same as the risk to persons aged 70 to 74 years. The JCVI advises that persons aged less than 70 years who are clinically extremely vulnerable should be offered vaccine alongside those aged 70 to 74 years of age. There are 2 key exceptions to this, pregnant women with heart disease and children.³

² <https://www.gov.ie/en/press-release/73add-solidarity-has-been-and-must-remain-the-hallmark-of-the-irish-response-to-covid-19/>

³

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/950113/jcvi-advice-on-priority-groups-for-covid-19-vaccination-30-dec-2020-revised.pdf

- **In Australia**, the Australian Technical Advisory Group on Immunisation (ATAGI) has also placed younger adults with an underlying medical condition, including those with a disability, in high priority and in second place (phase 1b) and alongside persons aged 70 and over. Persons aged 60-69 are placed in third priority (phase 2a).⁴
- **In Denmark**, the Danish Health Authority has identified persons with conditions and diseases that result in a significantly increased risk of severe illness from COVID-19, **and** their relatives and carers, as a group requiring priority vaccination, and places them ahead of otherwise healthy adults aged 65-84.

Indeed, the Health Information and Quality Authority (HIQA) in its advice provided to NPHE on 5 November on ‘extremely medically vulnerable groups with respect to COVID-19’⁵ points to the Danish model and the person-centred nature of its approach. HIQA’s advice also highlights the need to ensure that *“conditions associated with severe illness in Irish populations are reflected in the risk categorisations.”* It also underlined that *“less healthy adults, for example those aged 50 years and older with multiple chronic conditions...(...)...are at an increased risk of severe disease, yet this risk may not be sufficiently acknowledged”*. The HIQA report underlines that for several groups, such as people with rare diseases and inborn errors of metabolism, *“an absence of evidence of severe COVID-19 in these conditions should not be interpreted as an absence of a true association”*. HIQA recommends that a framework be established to ensure that the categorisation of risk groups can be updated as new evidence emerges. It references the work of the CDC in the US.⁶ HIQA’s appeal echoes guidance from the European Centre for Disease Prevention and Control (ECDC) which has called for national vaccination strategies which are “adaptable” and “continuously updated”.

The ECDC on 22 December 2020 published a report into the COVID-19 vaccination and prioritisation strategies in the EU/EEA.⁷ One of the conclusions arrived at by the ECDC suggests that *“If a COVID-19 vaccine is efficacious in preventing symptomatic disease in older adults but does not prevent transmission, the highest impact in terms of both deaths averted and life years saved is gained by vaccinating adults aged 60 years and over and younger adults with preconditions.”* This position clearly highlights the importance of considering high priority vaccination for persons with chronic and/or rare condition(s) aged 65 and under. The report elaborates *“When it comes to maximising the health benefits in an initial limited supply scenario, the highest efficiency in terms of deaths averted is gained from vaccinating adults aged 80 years and over, but in terms of life years saved the most efficient strategy is to extend the programme to include younger adults with preconditions.”*

Looking at the HPSC report into underlying conditions in confirmed cases of COVID-19 in Ireland published on 14 December 2020, evidence suggests that persons with underlying conditions **and** aged 65 and younger merit great consideration for vaccine prioritisation.⁸

Based on data available until 12 December, 93% of COVID deaths are of people with an underlying condition, 63% of

⁴ <https://www.health.gov.au/sites/default/files/documents/2021/01/australia-s-covid-19-vaccine-national-roll-out-strategy.pdf>

⁵ <https://www.hiqa.ie/sites/default/files/2020-12/Categorisation-of-extremely-medically-vulnerable-to-COVID-19-Advice-to-NPHET.pdf>

⁶ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/evidence-table.html>

⁷ <https://www.ecdc.europa.eu/en/publications-data/covid-19-vaccination-and-prioritisation-strategies-eueea>

⁸ https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary_1.0v%2014122020.pdf

COVID hospital admissions are of people with an underlying condition, 88% of COVID ICU admissions are of people with an underlying condition, and perhaps most importantly, 66% of COVID cases reported among people with an underlying condition (either in the community or in hospital) are among persons who are aged 65 or younger.

It is worth noting that these figures included in the HPSC report do not include individuals affected by the third wave of the pandemic, where many people with underlying conditions are likely to have been affected.

The involvement of representatives of people with disabilities and chronic and/or rare condition(s) on key policy and/or decision-making bodies to ensure public participation, transparency, and accountability

Leaving the current order of priority categories aside, there are a number of aspects to the national immunisation plan which will require a person or patient-centred approach, not least,

- The identification of persons eligible for vaccination – *as a priority* – due to their physical health status;
- The selection of vaccine(s) to administer to ensure maximum protection for those whose health is already compromised by chronic and/or rare condition(s);
- The spacing of the administration of first and second doses to ensure maximum protection for those whose health is already compromised by chronic and/or rare condition(s);
- The preparation of targeted public health information for persons managing chronic and/or rare condition(s) and considering vaccination.

Each of the elements detailed above will require the support of patient organisations, but yet patient organisations remain largely absent from both ongoing policy discussions and decision making. The effective disbandment of the NPHEP Sub-Group on Vulnerable Persons has left a large void in the communication between patient organisations and government and public officials. The failure to include a patient (or even a public) representative on the High-level Task Force is another challenge to transparency and accountability, and perhaps most importantly, patient and public confidence. To change the trajectory, the Government should immediately appoint patient representatives to key policy discussion and decision-making bodies tasked with the detailed implementation of the national immunisation plan.

Identification of persons with medical conditions

Different patients have experienced the pandemic in different ways – depending on many factors – including their condition, their prognosis, their medication, their treatment plan, and their family supports. Patients bearing the highest risk and the highest burden must be prioritised. However, unlike the Government’s other priority categories which are readily identifiable by age, institution or profession, the prioritisation of patients ‘*aged 18-64 with medical conditions which put them at high risk of severe disease*’ will not be easy – especially in the event of limited supply or need for a specific vaccine. A scenario should not be allowed to unfold where certain patients attending a particular hospital or healthcare professional have access to the vaccine faster - either by virtue of over-supply to a particular location or because of the proactive measures taken by one consultant or another to

identify or prioritise their patients for vaccination. The Government must work with patient organisations and healthcare professionals to devise a process which is equitable and evidence-based.

Selection of vaccine for administration to persons with medical conditions

Patients also want to know what vaccination will be administered to them. Early recipients of vaccinations are receiving Pfizer/BioNTech and Moderna vaccines, but those in later priority categories may end up receiving the AstraZeneca vaccine (if approved for use in the EU by the EMA on 29 January or thereafter). The AstraZeneca vaccine has typically reported lower efficacy levels than the Pfizer/BioNTech and Moderna alternatives. This naturally raises some concern, not least among patients with chronic and/or rare diseases who due to the high risk that COVID-19 poses for severe disease and/or death cannot afford to take any chances. For them, a less than effective vaccine is the same as no vaccine at all. Without the assurances of a robust immune response, they will not be able to re-join society in any meaningful way and they will therefore continue to face isolation and exclusion and all its associated ills. The Government must work with patient organisations to understand the real and/or perceived concerns of persons with chronic and/or rare condition(s), and develop the appropriate research and public health information to manage expectations.

Spacing of first and second doses for persons with medical conditions

The spacing of first and second doses is also an important consideration for patients, whose physical health is already compromised by chronic and/or rare condition(s). As we see governments come under increasing pressure to secure adequate supply, we see the movement of the proverbial goalposts. In the UK, the spacing between first and second doses may run to 12 weeks, well in excess of the ECDC's recommended six-week window.⁹ Discussions around the interchangeability of vaccines, and the potential provision of one brand of vaccine for dose one and a second brand of vaccine for dose two have also sparked concerns. The ECDC is again clear in recommending, that until sufficient clinical evidence is available, the same product should be used for both doses. The Government must work with patient organisations to understand the real and/or perceived concerns of persons with chronic and/or rare condition(s) and develop the appropriate research and public health information to manage expectations.

Preparation of public health information for persons with medical conditions

Patients have many nuanced questions relating to their unique position as an individual requiring vaccination who already manages chronic and/or rare condition. They need to have these questions answered, and as yet, patient organisations are not fully able to do so. Patient organisations need to be made aware of the potential challenges. They need to be able to address questions about the efficacy of vaccines and about potential interactions with different medications. They also need to be able to walk them through how a vaccine can be administered to them in a way which provides maximum safety from infection (thereby maximising the benefit of all their cocooning endured to date). The Government and patient organisations must work in partnership to tailor public health information to the needs of persons with chronic and/or rare condition(s).

We are keen to start a regular, two-way dialogue between the Department of Health and patient organisation leaders. We are willing to join together to manage expectations, spread the word, and get things going; but for now, we are being kept at arm's length. Your invitation to prepare a submission has been the first engagement of its kind, and it is most welcome. We hope that it will prompt others to act in a similar vein. In the meantime, we continue to field daily calls from persons with chronic and/or rare condition(s) from around the country who remain confused, disappointed and exhausted from the toll which the high risk of COVID has exerted on their lives and the lives of their families and carers.

⁹ <https://www.ecdc.europa.eu/sites/default/files/documents/COVID-19-risk-related-to-spread-of-new-SARS-CoV-2-variants-EU-EEA-first-update.pdf>

About IPPOSI

The Irish Platform for Patients' Organisations, Science and Industry (IPPOSI) is a unique, patient-led partnership in Ireland and internationally. The platform brings together patient groups, scientists, clinicians, industry professionals, and other key decision-makers to build consensus on issues relevant to all involved in delivering treatments and innovations to people with unmet medical needs.

The IPPOSI vision is that the patient voice is at the centre of all health policy, care, research and innovation in Ireland. To that end IPPOSI develops and implements initiatives such as workshops, education programmes, citizen juries and conferences on policy, legislation, regulation related to health innovation in Ireland.

The 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 of 08 December can be accessed [here](#).

The letter was initially signed by 15 organisations (ALONE, Alpha-1, Asthma Society, COPD Support Ireland, CROI, Disability Federation of Ireland, Family Carers Ireland, Irish Cancer Society, Irish Kidney Association, Irish Heart Foundation, IPPOSI, Mental Health Ireland, MS Ireland, Neurological Alliance of Ireland, Rare Diseases Ireland and Sage Advocacy), with four further organisations joining afterwards (Chronic Lymphocytic Leukaemia Ireland, Irish Thoracic Society, Multiple Sclerosis Ireland, Muscular Dystrophy Ireland).

Our research into patient perceptions

On 21 January 2021, we launched an online survey to gather patient community perceptions around the topic of COVID-19 vaccines. In less than four days, we received over 500 responses from patients, and their carers, from around the country. The full findings from our survey can be viewed [here](#).

This submission details the issues and recommendations shared by the following 16 organisations

