

EQUITY. EVIDENCE. ENGAGEMENT.

28 January 2021

Dear Minister,

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We understand and appreciate that you are faced with many competing requests and that tough decisions need to be made. We must however ask that you take time to understand the particular concerns and issues facing patient communities across Ireland. Their challenges are magnified, their health is already compromised by a chronic and/or rare condition, their isolation and exclusion from society is real. In the spirit of cultivating a meaningful partnership with some of our most vulnerable citizens, we ask for considered engagement with the patient and carers community going forward, and a considered reply to this correspondence.

We share some of the most pressing concerns and issues facing patient and carer communities across Ireland in our brief summary, appended in full below. Our recommendations urge you to:

- consider greater priority for patients with chronic and/or rare diseases, particularly those deemed extremely medically vulnerable who are under 65 years of age, and their carers;
 - o In the UK extremely medically vulnerable people between aged 16-64 years are prioritised for vaccination with people aged 70-74 (*see information in box on page 4*).
- ensure priority for all frontline health and social care workers, including the essential staff who work with vulnerable groups, people with disabilities and chronic and/or rare conditions;
- provide a clear timeline for the completion of vaccinations for each priority category;
- provide clarity around how high-risk patients will be identified and called for vaccination;
- accelerate the introduction of available digital solutions, easing the logistical burden and facilitating a smoother and a traceable vaccination process;
- put in place the protocols needed to ensure that vaccination related information is being systemically and nationally collected, and updated and published on a daily basis;
- seek scientific, clinical, and ethical advice around vaccine selection and vaccine dose spacing for persons with high-risk conditions, making this advice publicly available;
- review the status of the NPHE Sub-Group for Vulnerable Persons and ensure that patient representatives are involved in policy and decision-making bodies tasked with the detailed implementation of the national immunisation plan;
- establish a regular, two-way channel of communication between the Department of Health, other relevant health stakeholders, and patient and carer organisations, ensuring tailored information reaches patients and patient concerns reach decision-makers.

We remain at your disposal to provide further clarification, or to engage in dialogue around how best to tackle some of these common interests. We look forward to your response.

Kind regards,

ALONE

Alpha-1 Foundation

Asthma Society of Ireland

Irish Cancer Society

Chronic Lymphocytic Leukaemia

Croi, Heart and Stroke

Cystic Fibrosis Ireland

COPD Support Ireland

Diabetes Ireland

Disability Federation Ireland

Family Carers Ireland

Irish Heart Foundation

IPPOSI

Irish Kidney Association

Muscular Dystrophy Ireland

MS Ireland

Neurological Alliance Ireland

Rare Disease Ireland

Irish Thoracic Society

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A summary of the concerns and issues facing patient communities across Ireland, and a collective appeal from 19 patient and carer organisations for equity, evidence, engagement across the implementation of the national immunisation plan.

Equity

It will not surprise you to learn of our disappointment following the government's decision of 15 December not to give greater priority to the vaccination of high-risk patients with chronic and/or rare diseases, especially those aged 65 and less (who are currently only seventh in line for vaccination). The failure to delineate between a patient-facing and non-patient facing healthcare professional (second and fourth priority categories) and the ambiguous sixth category of 'key worker' have been hard to explain to our patient members. As many of our members have been advised to exclusively cocoon since March of last year, some have had to give up their jobs, some have had to miss important medical appointments, some have had to home-school children indefinitely. They are not living, they are not able to participate in the 'new normal'; they are isolated, simply surviving, waiting for a vaccine. The pandemic has affected us all, but it has not affected us all equally – and patients with chronic and/or rare conditions are among the worst affected in terms of quality of life. **We continue to urge you to consider prioritising vaccination for patients with chronic and/or rare diseases, particularly those deemed extremely medically vulnerable and under 65 years of age, and their carers. We urge you to also immediately provide a clear timeline for the completion of vaccinations for each priority category, as has been done in other jurisdictions.**

Leaving the current order of priority categories aside, even within the seventh priority category, patients want to know who will be eligible for vaccination first. 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. Unlike 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. **We urge you to provide clarity around how high-risk patients will be identified (backed up with the appropriate clinical evidence), and we urge you to work with patient organisation leaders and healthcare professionals to identify solutions which meet the principles of moral equity and fairness. We urge you to accelerate the introduction of any available digital solutions to ease the logistical burden and to facilitate a smoother and a traceable roll-out of this part of the programme.**

Information on the progress of the implementation of the national immunisation plan must be collected and publicly shared. The current practice of providing only the [total number of vaccines administered](#) is not sufficient, and this only allows for misinformation and mistrust to spread. A breakdown is needed of the information by priority category and by geographic location, together with the details of which vaccines have been administered. **We urge you to put in place the protocols needed to ensure that vaccination-related information is being systemically and nationally**

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collected, and to start publishing more comprehensive public information on the vaccination process.

Evidence

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 confidence interval, 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.

Additionally, the National Immunisation Advisory Committee (NIAC) guidelines suggest that 'live' vaccines should not be administered to immunosuppressed persons. We are keen to confirm the safeguards in place to ensure that this guidance is understood and followed. We are also keen to educate people with chronic and/or rare conditions about the vaccine(s) which are most appropriate for them. **We urge you to seek scientific, clinical, and ethical advice around vaccine selection for persons with medical conditions which place them at high risk of severe disease or death. We also urge you to make the findings of this advice publicly available so that decisions can be understood, and expectations managed.**

Engagement

Patient organisation leaders currently field hundreds of calls daily from patients around the country. As we mentioned above, people have questions about who will be vaccinated, when, and with what vaccine. But they also have many more nuanced questions relating to their unique position as an individual requiring vaccination who already manages a chronic and/or rare condition. They need to have these questions answered, and as yet, patient organisations are not necessarily in a position to do so. We need support. We need to know what information to provide to our patient communities. We need to be made aware of the potential challenges they may face. We need to be able to address questions about the efficacy of vaccines and about potential interactions with different medications. We 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). We cannot do this alone. We need to be able to receive the appropriate and most up-to-date information from you. We also need to work with you to tailor this information appropriately for patient communities, and we need to bring to your direct attention the concerns and issues raised by patients. The latter is of particular importance given the de facto disbandment of the NPHEt subgroups, including the NPHEt subgroup on Vulnerable Persons which provided the only real mechanisms for addressing challenges to policy and decision-makers. **We urge you to immediately establish a regular and two-way channel of communication between the Department and other relevant health stakeholders, and the leaders of key patient organisations. We urge you to accept our offer to work in partnership to both ensure that information tailored for patient communities reaches them and to provide a mechanism for patient concerns and issues to be reported and addressed.**

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According to the [HPSC report into underlying conditions in confirmed cases of COVID-19 in Ireland](#), published on 14 December 2020 (and as such, not including individuals affected by the third wave of the pandemic):

- 93% of COVID-19 deaths are individuals with an underlying condition
- 63% of COVID-19 acute hospital admissions are individuals with an underlying condition
- 88% of COVID-19 ICU admissions are individuals with an underlying condition
- 66% of COVID-19 cases reported among individuals with an underlying condition are among individuals who are aged 65 years or younger

Yet despite the findings of the HPSC, individuals aged 65 years or younger are seventh in line for vaccination, the timeline for vaccination is still unconfirmed, and efficacy of the vaccine which will be made available to them is unknown.

Individuals considered extremely medically vulnerable have been cocooning for much of the pandemic. This means that available data is likely to underestimate the risk in this group. Considering data from the first wave in the UK, the UK's 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. Given the level of risk seen in this group as a whole, JCVI now 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.

This summary, and the recommendations put forward, are supported by the following organisations



The joint letter sent to the High Level Task Force on 08 December and signed by 18 organisations is available at <https://www.ipposi.ie/2020/12/07/patients-voice-covid-19-prioritisation/>

The submission made to the Joint Committee on Disability Matters on 26 January by 16 organisations is available at https://www.ipposi.ie/wp-content/uploads/2021/01/IPPOSI-Submission-to-the-Joint-Committee-on-Disability-Matters_final-all.pdf