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### **Proposal to decline some medicine funding applications on the Options for Investment list**

PWSA(NZ) acknowledges the intention behind this proposal and supports reform to increase transparency in how medicine funding decisions are managed, but we strongly disagree that removing the bottom 10-20% of applications from the OFI list is an appropriate way to do this.

If a more effective medicine becomes available to treat a condition, meaning an OFI-listed medication is no longer needed by a patient group, then that medication can be removed in consultation with the consumer group and expert advice. However, removing a medication simply because it is deemed low priority is neither fair nor equitable for patients living with rare disorders.

Whilst we are pleased that Pharmac has recently amended its definition of a rare disorder to align with the international definition and New Zealand's Rare Disorders Strategy, which will hopefully allow more medicines to be considered under Pharmac's Rare Disorders Pathway, it remains essential to recognise the barriers that rare disorder groups have experienced for medicines to receive approval under the consideration criteria.

Patient groups like PWSA have spent countless volunteer hours making submissions and advocating for medicines to be funded. Some of the issues to overcome include requesting a high-cost treatment for a small consumer group and the gaps in clinical specialism and expertise when assessing treatments for rare disorders. We believe that using the Factors for Consideration has disadvantaged many rare disorder medicines that could have been rated as low priority when compared against government health priorities and benefits for the wider society.

Medicines on the OFI list have been approved for the benefit they would provide to patients, and this list serves as a reminder of the additional government investment that is required for medicines in Aotearoa New Zealand to close the funding gap with overseas nations. To remove approved medicines from the OFI list only serves to create the appearance that New Zealand is funding a higher percentage of approved medications than before.

If the bottom 10-20% of medications were to be identified by Pharmac, this would have the same effect as removing those medications from the list in terms of the impact on commercial sensitivity. Therefore, it is difficult to comprehend the reasoning behind this proposal.