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AMA submission – Life Saving Drugs Program review

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The review of the Life Savings Drug Program (LSDP) raises difficult and complex issues – clinical, ethical and financial.

The AMA agrees people with rare and life-threatening disease should have access to subsidised treatments that will improve their quality of life, even if they cannot be cured and their lives saved. Australia is a prosperous nation that can afford to provide this assistance. However, there needs to be an appropriate balance to ensure funding is targeted to where it can provide the most benefit for the most people.

The AMA supports evidence-based medicine and the principles of the Pharmaceutical Benefits Scheme to provide universal access to appropriate medicines in an effective, efficient and equitable manner.

We consider the appropriate balance can be reached by determining subsidised access to medicines for rare diseases under a framework that considers equity of access across the whole Australian population, with subsidy decisions based on quantifiable evidence and consistently applied.

We also consider that the Pharmaceutical Benefits Advisory Committee process is an evidence-based and equitable system for providing affordable, sustainable access to cost-effective medicines for all Australians.

There are good arguments for absorbing the LSDP into the broader PBAC process, either under a subcommittee with the ability to make quick decisions or under a similar framework to the current Highly Specialised Drugs program. We do not have a view on which of these two options are most appropriate.

Whichever option is pursued, the AMA considers the future process for funding medicines for rare diseases must have the following characteristics.

- Medicines should be examined for efficacy, cost-effectiveness and financial impact, but with consideration given to the difficulties inherent in very small disease populations and the use of broader measures such as quality-adjusted life years. While difficult, it important to apply similar standards of evidence and cost-effectiveness to all medicines so that funding is directed to treatments that actually improve and/or save lives.

- Explicit, quantifiable, transparent and pre-agreed criteria should be developed for continuing or discontinuing funding for individual medicines, and for continuing or discontinuing subsidy for individual patients. These criteria are necessary to help doctors appropriately de-prescribe when there are strong emotions involved.

- Medicine sponsors should be required to fund post-subsidy research to inform ongoing funding decisions. In this way we can ensure that evidence of efficacy and cost-effectiveness can be further developed and funding decisions are well based.

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