

Senate Community Affairs Committee

ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Supplementary Budget Estimates 2015 - 2016, 21 October 2015

Ref No: SQ15-000725

OUTCOME: 1 - Population Health

Topic: Rare Cancers

Type of Question: Written Question on Notice

Senator: Di Natale, Richard

Question:

- a) What is the status of the progression for a National Plan for Rare Diseases?
- b) Rare Voices Australia received bipartisan support in 2014 to establish a rare disease registry, where is the progress of the planning to establish such a registry?
- c) Given that Australia has no official rare disease data, can this be addressed as inclusion in a census question?
- d) Given Western Australia now has its state Rare Disease Framework 2015-2018 published, what progress are the other states making towards this?

Answer:

- a) The need for a National Rare Diseases Plan (the Plan) for Australia was considered by the Australian Health Ministers' Advisory Council (AHMAC) in September 2013, but the Plan has not progressed further.

The Commonwealth Government is working closely with Medicines Australia, as part of the Access to Medicines Working Group, to revise the Managed Access Programme (MAP) framework and processes.

The new MAP will facilitate earlier access to drugs by patients in circumstances where the Pharmaceutical Benefits Advisory Committee (PBAC) considers there is a high and unmet clinical need for the proposed drug in the indication requested by the sponsor, but there is clinical and economic uncertainty with the evidence currently available.

In deciding whether it is appropriate to list a drug using MAP, the PBAC would consider the prevalence and severity of the disease, whether alternative therapies are available, and the extent to which the proposed drug is expected to meet the unmet clinical need.

- b) The Department of Health has not received a proposal from Rare Voices Australia on the development of a National Rare Diseases Register.
- c) Census questions are a matter for the Australian Bureau of Statistics.

- d) Individual jurisdictions determine their preferred policy direction regarding rare diseases and are best placed to provide advice on the development of any state based rare disease frameworks.