

Senate Community Affairs Committee

ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Budget Estimates 2015 - 2016, 1 - 2 June 2015

Ref No: SQ15-000319

OUTCOME: 2 - Access to Pharmaceutical Services

Topic: Life Saving Drugs Program

Type of Question: Written Question on Notice

Senator: Di Natale, Richard

Question:

There has been concerns expressed that the Issues Paper appears to be written only by the Department of Health and the issues raised are not representative of the rare disease community. As this is about life saving responses, why haven't their voices been heard and addressed?

Answer:

The Issues Paper was issued by the Reference Group for the Review of the Life Saving Drugs Programme. The Reference Group includes members with specific expertise in rare diseases.

The Issues Paper sought to elicit stakeholder views, including those of the rare disease community, on the main topics that emerged from public submissions to the terms of reference of the review, stakeholder presentations and meetings with the Reference Group up until 10 April 2015. The release of the Issues Paper was followed by public consultation until 18 May 2015.