PBS Process Improvements Stage 1

Public Consultation Submission: New Medicine Status Website (Consumer View)

Rare Voices Australia (RVA) was pleased to contribute to the recent webinar and to follow up with this submission to this Consultation. The aim of a Medicine Status Website (MSW) is to improve transparency on the progress of submissions through the PBS listing system, an intent that RVA is supportive of and has been calling for. Theoretically, the site will provide greater transparency on the various processes that take place following a recommendation, while equipping consumers with the tools they need to search for and monitor the status of medicines as they progress through the PBS listing process. It will assist consumers to ensure their voice is effectively incorporated into this process.

In regards to the proposed embedded table that will be updated regularly that is referred to in the *Draft Medicine Status - Consumer View Paper*, RVA calls for complementary infographics to appear on the website to increase the accessibility and user-friendly nature of the information presented. It would be useful for consumers to have access to a general infographic that outlines the PBS process visually, in addition to infographics for each individual listing. We believe this will help to communicate and break down the amount of information included in the table. RVA also fully supports the inclusion of definitions explaining the source and meaning of each field, in addition to a user guide. We are aware that the average person living with a rare disease does not typically understand the language used widely in the field of health technology assessment. We would also like to highlight that the website needs to accommodate people who may only be required to take note of the PBS process once over the course of their lifetime. There shouldn't be any expectation on the consumer to spend copious amounts of time understanding the PBS system.

Additionally, RVA calls for the Medicine Status Website (Consumer View) to make clear to consumers that the PBS is only one reimbursement pathway and to create linkages to the other pathways where appropriate. This is especially important and relevant in the rare disease space where consumers may encounter the PBS pathway, as well as the Life Saving Drugs Reform Program (LSDP) or even the Medical Services Advisory Committee (MSAC).

Special Pricing Arrangement (SPA)

On 1 July 2018, revenue rebates for some high cost medicines were reduced with the agreement of the relevant medicine manufacturers, and with a corresponding reduction in the published price of those medicines. An improved payment administration trial for certain high cost medicines with special pricing arrangements is also scheduled to commence from 1 July 2019.

While RVA supports greater transparency, history has shown that SPA is especially vital in achieving successful pricing negotiations and ensuring people living with a rare disease have timely access to the best available treatment. It is critical that recent and future changes do not impede on any pharmaceutical company's ability to negotiate as this will have a ripple effect on people living with a rare disease, reducing their ability to access medicines as required.

About Rare Voices Australia

Rare Voices Australia is a national, not-for profit peak organisation that works with all stakeholders to be the unified voice and advocate for all Australians living with rare disease.

Yours sincerely

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