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To whom it may concern

Re: PBS Process Improvement Stage 1 – the development of a Medicine Status Website (MSW) Consumer View

Stroke Foundation welcomes the Federal Government's commitment to improving the transparency, timeliness and efficiency of the Pharmaceutical Benefits Schedule (PBS) listing process.

The Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, developing clinical guidelines, facilitating research and supporting stroke survivors. Stroke Foundation is dedicated to empowering health professionals to deliver high quality best-practice care to stroke patients.

Stroke is a serious medical emergency, requiring urgent medical attention. With the right treatment at the right time, many people are able to recover from stroke. Australian stroke patients are benefitting from access to innovative medicines, devices and procedures that have undergone rigorous assessments for their quality, safety, and clinical- and cost-effectiveness. These publicly subsidised treatments are saving lives and reducing disability in stroke survivors.

Australia is facing the dual challenge of an ageing population and increasing rates of chronic disease, which is placing growing pressure on decision-making bodies such as the Pharmaceutical Benefits Advisory Committee (PBAC). In light of these challenges, increasing public awareness of and engaging consumers in the PBS listing process is essential to maintaining public confidence in the process. As such, Stroke Foundation supports the development of a MSW Consumer View as a means of improving transparency on the progress of submissions through the PBS listing system.

Listed below are a few points for consideration when developing the MSW Consumer View.

1. The following approaches may facilitate improved understanding of the PBS listing process:
 - › A *visual or diagrammatic representation* of the current PBS listing process, highlighting key stages and milestones, including where consumers have an opportunity to provide comments.

- › The provision of *indicative timeframes for each stage in process* based on historical averages may be useful; however, it will be important to make it clear that these could vary considerably depending on the nature of individual submissions. A clear explanation is needed of the time lag between a positive PBAC recommendation, and when consumers are able to access a new medicine, and what steps need to take place during this period.
 - › A more detailed explanation of how *consumer input* is integrated into the PBAC decision-making process is needed, as is specific instructions of how consumers can provide comment on individual submissions.
2. The MSW Consumer View needs to be *more consumer-friendly and engaging, both visually, and in terms of the language used*, than the current PBS website. An example of this is the PBAC calendar, which in its current form is targeted primarily at submission sponsors and industry more generally. The use of specific terms such as 'Responsible Persons' and 'Discussants' is a barrier for consumers, and the inclusion of a glossary of terms may be useful.
 3. Providing an *overview of Australian Government Health Technology Assessment (HTA) processes for reimbursement*, not just for medicines through the PBS, but for medical services, devices and consultations (Medicare Benefits Schedule) and for new devices with existing MBS item numbers (Prostheses List), may provide some useful context for consumers.
 4. It would be very useful if the *search function on the MSW Consumer View could be optimised* to enable all medicines indicated for a particular condition or disease, such as stroke, to be retrieved, as this is often of interest to consumers and patient organisations.

Thank you for the opportunity to provide feedback on the proposed MSW Consumer View.

Yours sincerely,



Sharon McGowan
Chief Executive Officer
Stroke Foundation