



# PREPARING FOR PBAC CONSUMER COMMENTS CARERS AND FAMILY MEMBERS



The tip sheet is for carers and family members who may wish to make a Consumer Comment when the Pharmaceutical Benefits Advisory Committee (PBAC) is assessing whether a medicine should be subsidised under the Pharmaceutical Benefits Scheme (PBS) list.



## AS A CAREGIVER, YOU MAY WISH TO:

- support a loved one by helping them with their comment or making a comment on their behalf if they are unable to comment
- make a comment about the impact on you as a caregiver
- or do both.

Sharing the impact of caring for your loved one (be that full or part time) may be helpful. Things like whether it has meant changes to your employment status, social interactions and your own physical and mental health and wellbeing are all things the PBAC may consider.

## BEING PREPARED

1

Sign up to PBS [news list](#) so you can see which medicines it is assessing and when Consumer Comments are needed. (If you don't want to sign up to the news list, we publish their agendas on [our Facebook page](#).)

2

Find out what medicines are in the pipeline. Soon more information will be available to Australians, but these ideas may help.

- Talk to your doctor or support group.
- Networking. If you can't attend conferences and training days, look for opportunities to connect online or in your local community.
- Check out useful websites (see next page) where you can find out what medicines are in trials in Australia, what regulators have approved for use here or overseas, and what PBAC is assessing currently.

3

Find out what information is wanted. It is essential that you understand that PBAC works by answering questions with specific information or evidence. So, a large number of Consumer Comments from patients stating they need the medicine will have no impact on the PBAC advice. Whereas one or two Consumer Comments containing specific information about why a medicine is important based on your experience, needs and preferences can impact PBAC advice. Knowledge of the way services are provided and treatments are used in practice is also valuable.

Check out [what sort of information PBAC is looking for](#) and our tip sheets including: including [PBAC Consumer Comments Dos and Don'ts](#) and [advice from an experienced patient](#).

4

Ask questions. Knowing how Consumer Comments are used is important for having a voice and adding something valuable to the process.

- Contact the Consumer Engagement and Evidence Unit, email: [HTAconsumerengagement@health.gov.au](mailto:HTAconsumerengagement@health.gov.au)
- Take part in a Patient Voice Initiative workshop or Facebook event or discussion
- Talk to a PBAC Consumer Member.

5

Identify what you know. That sounds a bit obvious, but sometimes we don't realise how much we know from caring for someone with a condition. Because caring for someone with a condition is not just learning about the condition and treatments, it's about learning how to care for and live with your loved ones' condition. PBAC already has all the trial data and economic models and information about the disease or condition. What they don't know is all the things you've learnt by living with a disease or condition.

- Use the questions on the Patient Voice Initiative 'Knowledge Reflection Sheet' to reflect on your experience.
- If you keep a journal, review it to see if it reminds you of insights to share with PBAC.
- Reflect on the issues you've sought help

and advice with from your doctor, support groups, including online groups.

- Keep notes or even a draft comment so that so that it is easier to put in a Consumer Comment no matter what you are juggling when the medicine is on the PBAC agenda.
- Find out if your patient group is making a comment and if you can contribute in any way.



## ONLINE RESOURCES

Useful Sites for finding out what medicines may be coming

### Medicines in clinical trials in Australia

- ▶ [Australian New Zealand Clinical Trials Registry](#)

### Medicines approved for sale in Australia

- ▶ [Australian Register of Therapeutic Goods](#)

### Overseas bodies who approve medicines for sale in their area

- ▶ [US Food and Drug Administration \(FDA\)](#)
- ▶ [European Medicines Agency \(EMA\)](#)

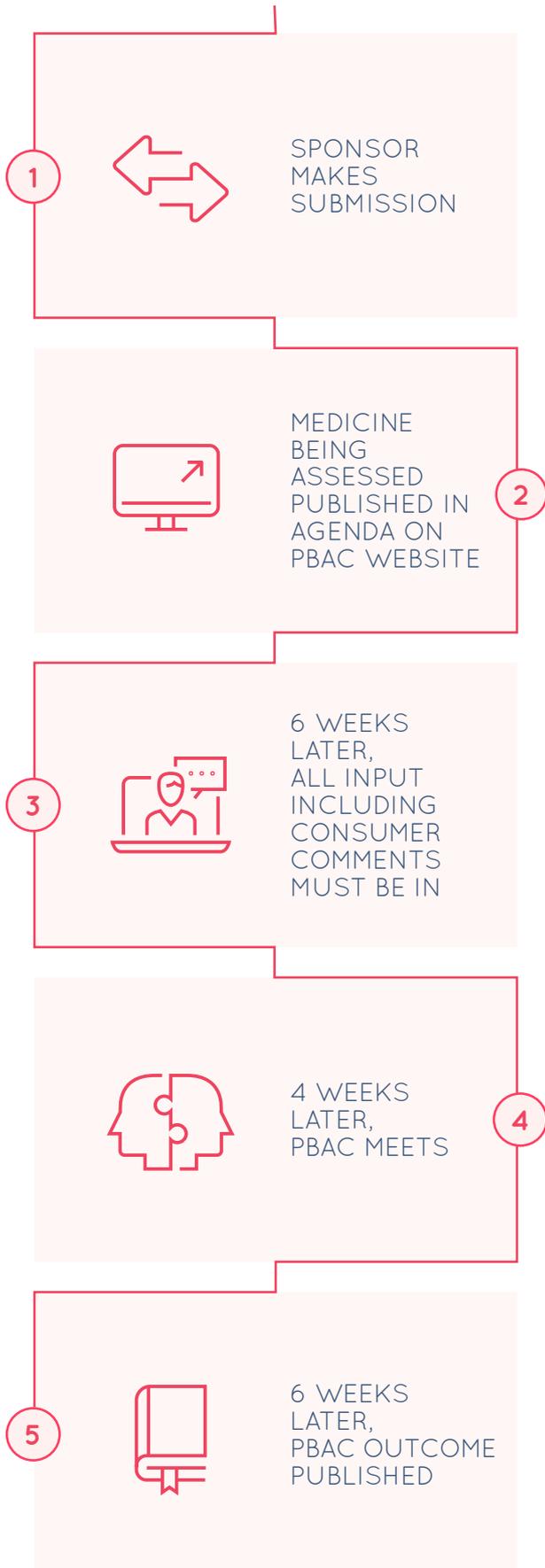
### Medicines submitted to PBAC

- ▶ [Medicines Status Website](#)



# PBAC ASSESSMENT TIMELINE

17 weeks from start to finish



## MAKING A COMMENT

1 When the medicine of interest is published on the PBAC agenda, note the date that your comment is due. It will be 6 weeks from the time the agenda is published.

2 Start ASAP so you don't miss the deadline.

3 Find out everything you can about the sponsor's (usually manufacturer or importer) submission for the medicine. This may involve contacting the sponsor because the PBAC is restricted in what it can publish. You want to know how it is requesting the medicine is used, for example:

- what condition, stage and/or subgroup
- where and when in the treatment process
- what has the sponsor compared it to (the comparator)
- specific risks and benefits of the medicine.

4 Check your draft against the advice in:

- [“How to make a difference”](#)
- [‘Dos and don’ts when making a PBAC Consumer Comment’](#)
- [“Tip sheet for submitting Consumer Comments to the PBAC”](#)

5 If you can't use the online form, you can make your comment by letter or it may even be accepted by phone. Speak to the Consumer Evidence and Engagement Unit to find out.