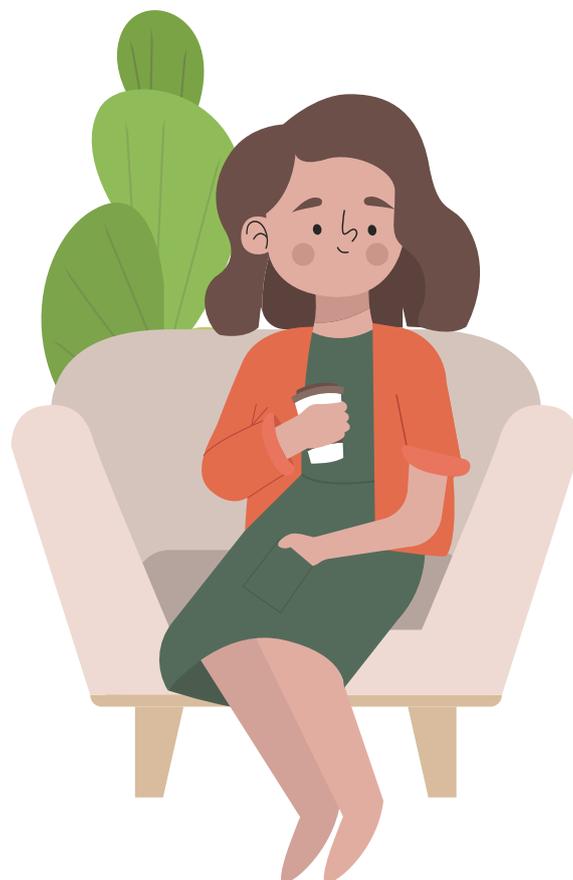




## PREPARING FOR PBAC CONSUMER COMMENTS PATIENT GROUPS



This tip sheet has been written to help patient groups or health consumer organisations get ready to provide input to the Pharmaceutical Benefits Advisory Committee (PBAC) before a treatment is listed on the agenda. By being prepared and having a plan, you may be better equipped to provide valuable input to the PBAC assessment.

To find out when a new PBAC agenda is published, sign up to PBS [news list](#). We also publish PBAC agendas on the Patient Voice Initiative [Facebook page](#).

Providing input to the PBAC, is an opportunity for patient groups to add information that is not captured in the data submitted by the sponsor. It can also help PBAC better understand the evidence and address uncertainties.

### BEING PREPARED

1

#### **Get informed about upcoming treatments.**

New medicines go on the PBAC agenda when a sponsor (usually the company that develops the medicine) makes a submission to PBAC. So it's useful to know what treatments are in medicine developers' pipelines. You could do this by:

- Checking out Useful Websites (see box) to find out what medicines are in trials in Australia and what regulators have approved for use here or overseas.
- Building relationships with similar patient groups overseas who may have access to information sooner or alternative sources of information. Groups in the UK, USA and Canada may be especially helpful.
- Watching out for training days and conferences. If you can't attend in person, look for opportunities to connect online or in your local community. We share many opportunities on our Facebook page.
- Letting a company know about your group and interest in being kept up-to-date about new treatments if it is developing a medicine for the condition you support.



## USEFUL WEBSITES

For medicines that may be in the pipeline, see:

- ▶ [Medicines in clinical trials in Australia](#)
- ▶ [Medicines approved for sale in Australia](#)
- ▶ [Medicines approved in the United States of America](#)
- ▶ [Medicines approved in the European Union](#)

[For medicines already assessed](#) or being assessed by PBAC, see

- ▶ [Medicines Status Website.](#)
- ▶ [Office of HTA consultation hub](#)

2

**Identify information you already have about the needs of your community** because although at this stage you may not have information about a specific, new treatment, PBAC always finds it helpful to know about challenges with current treatments as well as unmet needs and side effects.

Many patient groups already have some of this information in:

- patient correspondence
- social media threads
- information requests
- reports
- phone logs
- past surveys
- registries
- research into patients' needs, preference or experiences
- reports and work by other patient groups. For example, countries such as Canada, England and Scotland use similar processes to assess new medicines and patient groups there may have published or be willing to share their submissions.

3

**Identify the sort of extra information you might want.** At this stage, you will not know the details of the sponsor's submission to PBAC, but you can consider if your existing information will be useful or if you might want to gather further information. To find out what sort of information is useful to include in input to PBAC you can:

Look at these links:

- [PBAC's Consumer Comment page](#)
- [How to make a difference](#)
- [Tip sheet from a patient experienced in submitting to PBAC](#)
- [Knowledge Reflection Sheet](#)
- [Consumer Comments dos and don'ts](#)

Ask questions.

- While the Patient Voice Initiative offers general advice, speaking to the Consumer Evidence and Engagement Unit is invaluable if you have knowledge of a new treatment that is expected to go to PBAC. Email: [HTAconsumerengagement@health.gov.au](mailto:HTAconsumerengagement@health.gov.au) or talk to a PBAC Consumer Member.

Attend a Patient Voice Initiative event.

4

**Think of the best way to gather further information** taking account of your resources, the burden on your members and the value of the information. For example, if you have a strong understanding of the information needs of PBAC and the medicine pipeline, you might be able to gather information that is useful for multiple PBAC submissions or targeted towards one important submission. Consider what you could do in-house (such as surveys or discussion groups) and what could be done externally by a researcher. See our [video series](#) for more information about working with researchers.

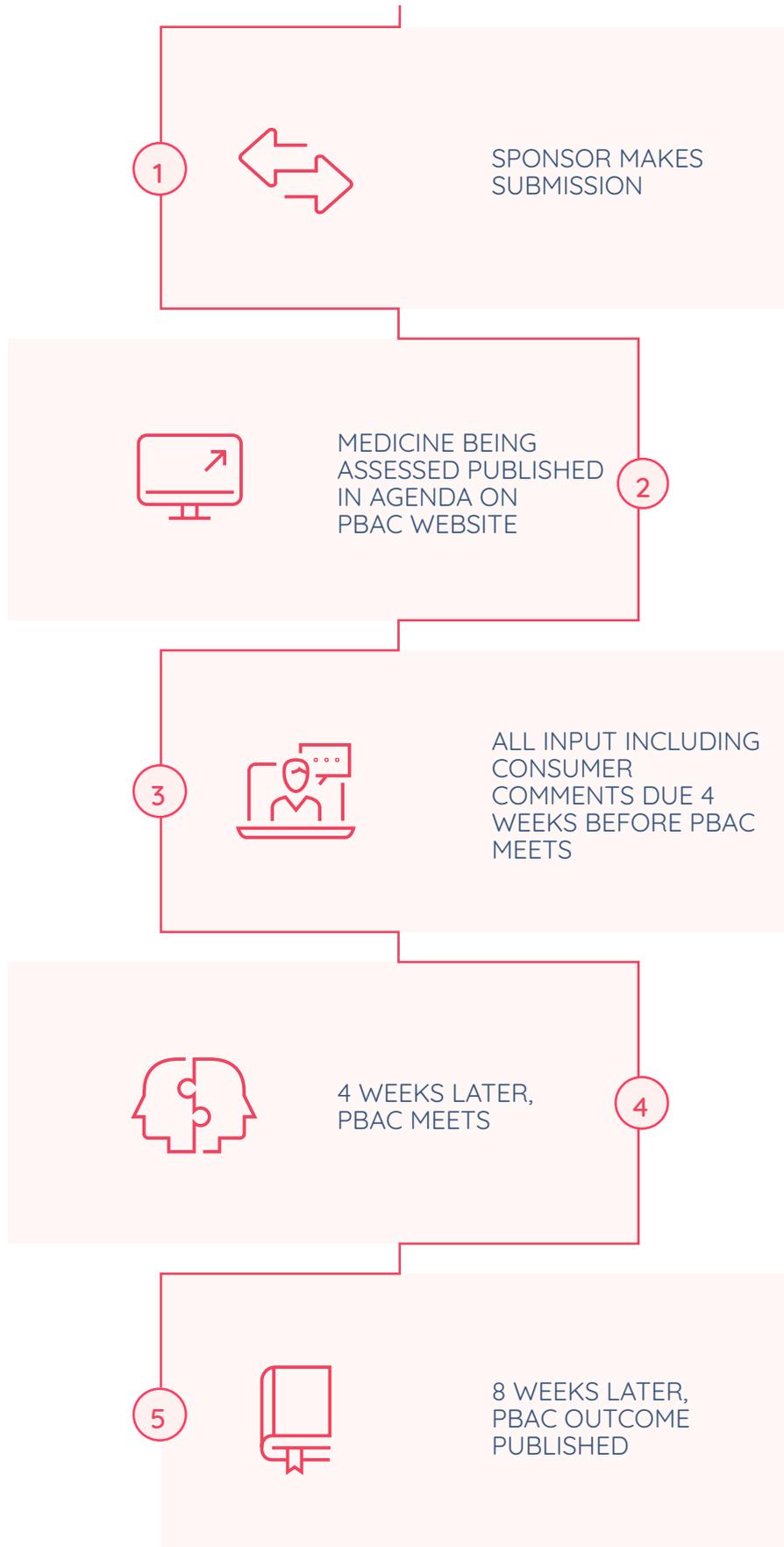
If a large number of medicines are in the pipeline for your members, you may want to consider how you will decide which medicines to prioritise. This can be difficult and should include discussion with your members. It can be worth considering if there is something different or special about the new medicine, for example:

- does it provide treatment for a group of patients with limited treatment options?
- does it work in a new way?
- is it administered differently (such as change from injection to tablet or hospital to home)?
- is it a change in the way it is packaged (such as different number of tablets in a box or different dose)?
- does it have different risks or side effects?
- is it a treatment where hearing your patient community's perspective would be beneficial?

Another option is to think about resources to help encourage your members to make individual comments.

# PBAC ASSESSMENT TIMELINE

17 weeks from start to finish



# PROVIDING INPUT TO PBAC

If you decide that providing input to PBAC is important, you might give input on behalf of your members or encourage them to make Consumer Comments or do both, but whatever you do it's useful to remember that the number of Consumer Comments will not influence PBAC. The content may influence PBAC if it addresses gaps or uncertainties in the evidence PBAC is considering. Your members' Consumer Comments can be an important part of this when they show PBAC the reality of living with a condition or using treatments, but this opportunity is lost when Consumer Comments repeat words that are copied from a form letter developed for a campaign.

1

When the medicine of interest is published on the PBAC agenda, note the deadline for input (or [Consumer Comments](#)).

2

Begin work on your input as soon as you can. Using the information you've discovered about what PBAC needs, draft an outline for your input with headings for the areas you plan to include so that you're not staring at a blank page the night before the deadline. Remember, it's the content that matters, not the length or even typos. Decision makers are looking for helpful information, not perfection.

If you have specific questions about what is being proposed you could:

**Contact the sponsor to find out what they applied for, including:**

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

**Contact the Consumer Evidence and Engagement Unit for advice to ensure you are on the right track.**

3

Put in place your plan for finding any further information you may need to inform your input. This could include collecting information from surveys, using a closed Facebook group, asking specific questions in one of your discussion groups.

4

Check your draft against the advice in:

- [How to make a difference](#)
- [Tip sheet from a patient experienced in submitting to PBAC](#)
- [Consumer Comments dos and don'ts.](#)

5

Submit your input or comment. The PBAC accepts input through its website, but also by letter or email. If you have questions about the process you can contact the Consumer Evidence and Engagement Unit.

