



# Copy of public consultation survey for items to be considered by the PBAC (July 2022)

<https://ohta-consultations.health.gov.au/ohta/online-comments-to-pbac-july-2022/>

**Consultation closing: 25 May 2022**

## Overview

Consultation is now open for items listed on the **July 2022 PBAC agenda**.

The PBAC welcomes input from patients, carers, health professionals, consumer groups or organisations and members of the public on medicines submitted for PBAC consideration.

The PBAC considers these public consultation inputs when considering the clinical and economic evidence presented by the applicant.

Input can be submitted via the **online survey**.

**There is the option to upload a file with your submission.** The preferred file types are PDF or Microsoft Word, however other file types will be accepted, provided they are no larger than 25mb. If your file is too large, or you wish to upload more than one file, please contact [commentsPBAC@health.gov.au](mailto:commentsPBAC@health.gov.au).

You can save and come back at any time to your response before the consultation close date. Once you have submitted, a copy of your submission will be emailed to the contact email address provided.

**Should you wish to provide input on another medicine, you will need to start a new survey.**

Please note that we may be updating this survey in the coming months to provide additional guidance and welcome suggestions on ways to further improve this process.

## Privacy and consent

### **Privacy Information**

Your personal information is protected by law, including the *Privacy Act 1988* (Privacy Act) and the Australian Privacy Principles (APPs), and is being collected by the Department, via Citizen Space, for the purposes of conducting a consultation process in relation to an application submitted to the Office of HTA. The Department will collect your personal information at the time that you provide a submission. To protect privacy, do not include identifying personal or sensitive information about another individual (third party).

### **More information about privacy**

You can obtain a copy of the Department's privacy policy (<https://www.health.gov.au/resources/publications/privacy-policy>) by contacting the Department using the contact details set out below. The Department's privacy policy contains information about:

- how you may access the personal information the Department holds about you and how you can seek correction of it; and
- how you may complain about a breach of
- the APPs; or
- a registered APP code that binds the Department; and
- how the Department has dealt with such a complaint.

You can contact the Department by telephone on (02) 6289 1555 or free call 1800 020 103 or by using the online enquiries form at: <http://www.health.gov.au/>.

### **How your input will be used**

All input from individuals will be made available in **summary** form to the sponsor of the application and the PBAC. No identifying information about individuals or third parties will be included in the summary. This type of information will be removed by the Department.

All input from groups or organisations will be provided in full to both the PBAC and its subcommittees and the sponsor of the medicine. Any identifying information relating to third parties detected will be removed prior to distribution.

In addition all input received will be noted in the relevant Public Summary Document. Public Summary Documents are available approximately four (4) months after the PBAC meeting and outline the PBAC discussion and advice. See the **PBAC calendar** <<http://www.pbs.gov.au/info/industry/usefulresources/pbs-calendar>> for publication dates.

Please indicate your consent below.

### **Consent** *(Required)*

I have read the above text on how public consultation input will be used and consent to the input being used as described above

## Contact details

Below is a section to provide your contact details. These details are not made public or shared with the PBAC. We ask for these individual details only to ensure submissions are recorded accurately and can be confirmed, if required.

**1 What is your name? (Required)**

**2 What is your email address? (Required)**

(If you enter your email address then you will automatically receive an acknowledgement email when you submit your response.)

**3 Are you providing input as an individual or on behalf of an organisation? (Required)**

We recognise that individuals can cross multiple categories. Please choose a category that best describes the primary reason for your submission. *Please select only one item*

- Individual who would like to access the medicine to treat own health condition
- Individual who has used this medicine for own health condition
- Parent or partner of an individual from above two groups
- Consumer group/organisation
- Health professional working in the area
- Medical/other organisation
- Other interested individual (including family members, friends, or members of the public)

For noting:

- Input from individuals will be deidentified, collated and summarised before provision to Applicants and the PBAC.
- Input made by organisations (consumer, medical or other) will be shared in full with applicants and the PBAC.
- If you are a health professional with experience treating the condition or using the medication and are providing input that represents your own views, select 'Health professional'. If you are a health professional providing input on behalf of a group of clinicians or an organisation, please select 'Medical/other organisation'.

**4 If you selected consumer group/organisation, or medical/other organisation above, please provide the name of the group/organisation.**

**5 What is your phone number? (Required)**

**6 What is your state?**

Please select your state. *Please select only one item*

- ACT
- TAS
- NSW
- QLD
- WA
- SA
- NT
- VIC

**7 Select the medicine you would like to provide input on *(Required)***

Select a medicine. *Please select only one item. To provide input for more than one medicine you will need to fill out another survey.*

- ADALIMUMAB - Yuflyma®: Severe Crohn disease; Moderate to severe ulcerative colitis; Severe active juvenile idiopathic arthritis; Complex refractory fistulising Crohn disease; Severe active rheumatoid arthritis; Severe psoriatic arthritis; Ankylosing spondylitis; Severe chronic plaque psoriasis; Moderate to severe hidradenitis suppurativa
- ANIFROLUMAB - Saphnelo®: Systemic lupus erythematosus
- APALUTAMIDE - Erlyand®: Prostate cancer
- ASCIMINIB - Scemblix®: Chronic myeloid leukaemia
- ATEZOLIZUMAB - Tecentriq®: Non-small cell lung cancer
- AZACITIDINE - Onureg®: Acute myeloid leukaemia
- BECLOMETASONE WITH FORMOTEROL - Fostair® 200/6: Asthma
- CEMIPILMAB - Libtayo®: Cervical cancer
- DAUNORUBICIN WITH CYTARABINE - Vyxeos®: Acute myeloid leukemia
- DUPILUMAB - Dupixent®: Chronic severe atopic dermatitis
- EPTINEZUMAB - Vyepti®: Chronic migraine
- ESKETAMINE - Spravato®: Depression
- EVOLOCUMAB - Repatha®: Hypercholesterolaemia
- FINERENONE - Kerendia®: Diabetic kidney disease
- HUMAN MENOPAUSAL GONADOTROPHIN - Menopur® 600; Menopur® 1200: Assisted Reproductive Technology
- LEUPRORELIN ACETATE - Eligard® 6 month: Central precocious puberty
- MIDAZOLAM - Zyamis®: Epilepsy
- NATALIZUMAB - Tysabri®: Multiple sclerosis
- NIVOLUMAB - Opdivo®: Urothelial carcinoma
- NIVOLUMAB - Opdivo®: Oesophageal carcinoma or gastroesophageal junction carcinoma
- OLAPARIB - Lynparza®: Ovarian cancer
- PEGVALIASE - Palynziq®: Phenylketonuria
- PEMBROLIZUMAB - Keytruda®: Urothelial cancer; Colorectal cancer; Primary Mediastinal B-cell Lymphoma; Classical Hodgkin Lymphoma
- POLYETHYLENE GLYCOL 400 WITH PROPYLENE GLYCOL - Optix®: Severe dry eye syndrome, including Sjogren's syndrome
- PROGESTERONE - Cyclogest®: Infertility

- RELATLIMAB WITH NIVOLUMAB - Opdualag®: Melanoma
- RISANKIZUMAB - Skyrizi®: Crohn disease
- ROMOSOZUMAB - Evenity®: Osteoporosis
- RUXOLITINIB - Jakavi®: Graft versus host disease
- SAPROPTERIN - Kuvan® : Phenylketonuria
- TEZEPELUMAB - Tezspire®: Asthma
- TRASTUZUMAB DERUXTECAN - Enhertu®: Breast cancer
- UPADACITINIB - Rinvoq®: Ulcerative colitis
- USTEKINUMAB - Stelara®: Severe Crohn disease; Severe chronic plaque psoriasis
- USTEKINUMAB - Stelara®: Ulcerative colitis
- VOSORITIDE - Voxzogo®: Achondroplasia

**8**      **How did you find out about this consultation? *(Required)***

## PBAC public consultation survey

The PBAC welcomes input from anyone with an interest in the medicine proposed to be listed on the Pharmaceutical Benefits Scheme (PBS). You can submit input by answering the five (5) questions below and/or by uploading a file. You can choose to answer as many of the questions as you like but providing as much detail as you can will be most helpful for the PBAC. Your input will be saved so you can come back at any time to your response before the consultation close date. A copy of your submission will be emailed to the contact email address provided.

### **1 Please outline your experience with the medical/health condition**

#### ***Points for consumers to consider***

*How does this condition/disease impact your life? Try to be as specific as possible including impacts on your everyday activities, work, family, friends, mental and emotional health.*

Please provide your comments

### **2 How is the medical/health condition currently treated?**

#### ***Points for consumers to consider***

*What symptoms can not be controlled with the current treatment?*

*Do you experience any particular difficulties accessing current treatment (for example due to eligibility requirements, or where or how the treatment is given)?*

### **3 What do you see as the advantages of this proposed medicine, in particular for those with the medical condition and/or family and carers?**

#### ***Points for consumers to consider***

*What specific health benefits or changes to quality of life are you expecting from this treatment?*

*If you have used this medicine what was your experience? What changed for you?*

*Are there benefits such as the way the medicine is delivered (for example, tablets rather than injection) or where the medicine is given (at home or in hospital)*

Please provide your comments

### **4 What do you see as the main disadvantages of this proposed medicine?**

#### ***Points for consumers to consider***

*Have you heard of any side effects from this medicine? Do you consider these to be manageable?*

*What side effects would stop you from taking this medicine?*

*If you have used this medicine, did you experience any side effects?*

Please provide your comments

### **5 Please provide any additional comments you would like the PBAC to consider.**

If you would like to upload a file for this medicine please do so below.

Please note we do not accept petitions, duplicate submissions from the same author, form letters (multiple copies of the same statements of support for access), or any material that is inappropriate in language or tone.

Please ensure your file is under 25mb in size. The preferred file types are PDF or Microsoft Word, however other file types (for example .jpg, .png, .mp3, .mp4, etc) will be accepted.

Recorded consultation input (video or audio) will be accepted by PBAC, provided the input is no longer than 10 minutes in duration. If the files are larger than 25mb, please email the recording file or a link to the recording file (hosted via another accessible platform such as YouTube or Vimeo) and/or its transcript directly to [commentsPBAC@health.gov.au](mailto:commentsPBAC@health.gov.au).

Recordings longer than 10 minutes may not be considered by the PBAC.

Should you have any difficulties submitting this form, or you would like to submit a file(s) larger than 25mb, please contact [commentsPBAC@health.gov.au](mailto:commentsPBAC@health.gov.au).

**6 We are considering revising the consultation survey for future PBAC consultation rounds, along with providing additional guidance. Are there any suggestions you would like us to consider as part of this process?**

## Declaration of interests

### Declaration of Interest Statement

The purpose of this declaration is to discover any financial, professional or personal interest on the part of a person, or on the part of their immediate family, who is providing consumer input to the PBAC.

### Information on declaration of interests

For example, a patient has an interest in a particular medicine, because they are currently using it, and wish to see it listed on the PBS. A doctor may be providing comments and has also been involved in clinical trials investigating this medicine. A family member may want to provide comments on a particular medicine that another relative is using, and separately may also have shares in the company which manufactures a number of pharmaceutical drugs, including this specific item. Such interests may affect or have the appearance of affecting a person's view on the merits of a drug, vaccine or medicinal preparation being considered by the PBAC. The existence of such interests may be a 'conflict of interest'.

A conflict of interest is declared so that information provided can be assessed fairly and in a transparent manner. The declarations are confidential to the PBAC, and do not prevent anyone from providing their comments.

A conflict of interest can be declared, but does not mean a person should not still provide their comments.

A **financial interest** may include, but is not limited to, any of the following involvement with companies or other organisations engaged in the development, manufacture, marketing or distribution of vaccines, drugs and medicinal preparations:

1. current shareholdings;
2. board memberships or other offices;
3. paid employment or contracting work;
4. grants
5. hospitality (including conferences, travel).

A **professional interest** may include, but is not limited to, involvement in any of the following:

1. development, manufacture or marketing and distribution of vaccines, drugs and medicinal preparations;
2. making a public statement about that company or a drug or other product of that company.

A **personal interest** may include, but is not limited to, any of the following:

1. where you are writing to support a drug being listed on the PBS, because you have a condition or illness for which that drug may be being considered by the PBAC;
2. an immediate family is aware that a relative close to them suffers from a condition for which a drug before the PBAC may be being considered by the PBAC;



3. where you or your immediate family has strong personal or religious beliefs about a drug or treatment under consideration by the PBAC.

Please include any declarations you wish to make regarding the PBAC submission upon which you are commenting. *(Required)*

*Please select all that apply*

- No conflicts
- Financial conflicts (describe below)
- Professional conflicts (describe below)
- Personal conflicts (describe below)