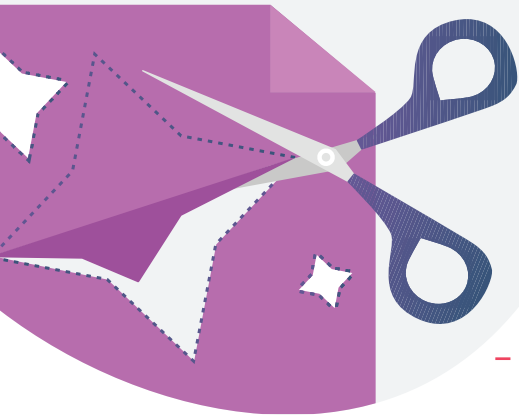


Patient Voice Initiative

PBAC CONSUMER COMMENTS DOS AND DON'TS

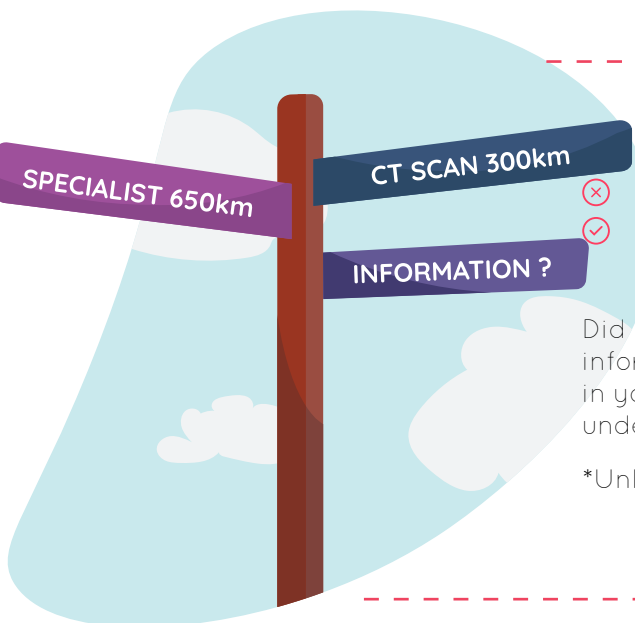
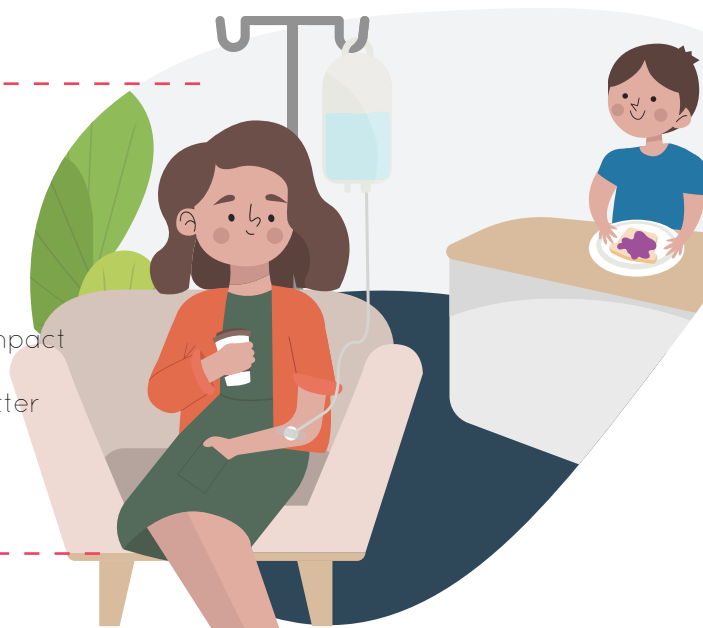


- ⊗ **DON'T CUT AND PASTE**
- ✓ **DO SHARE WHAT YOU KNOW**

PBAC is not influenced by the number of Consumer Comments it receives because its advice is based on evidence. Consumer Comments are a way of using your lived experience expertise to inform PBAC about issues that may be missing in that evidence.

- ⊗ **DON'T GIVE GENERAL INFORMATION**
- ✓ **DO BE SPECIFIC**

Does the fatigue or pain that comes with your condition impact on your ability to work, go to school or have a social life? Explaining the wider impact of symptoms helps people better understand your needs and what you experience.



- ⊗ **DON'T GIVE NUMBER OF CASES***
- ✓ **DO EXPLAIN THE DIFFICULTIES OF HAVING A RARE DISEASE**

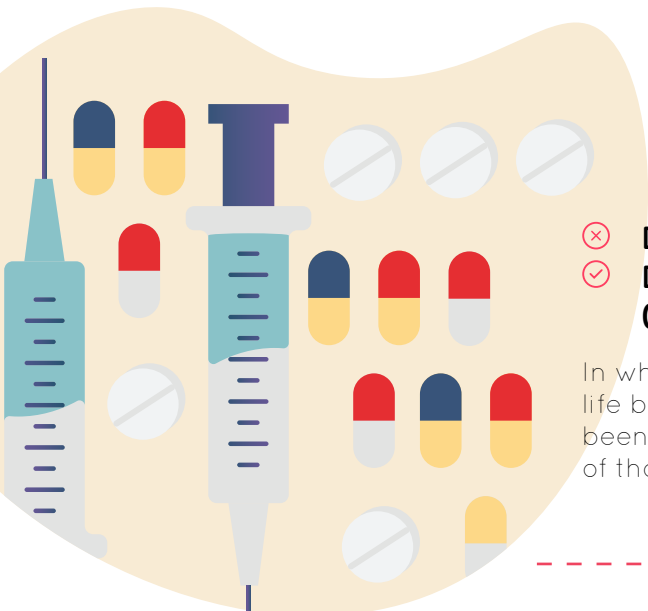
Did having a rare disease make it hard to get a diagnosis and information? Is it difficult to access expert doctors and treatment in your area? Information like this can help people better understand your needs.

*Unless you disagree with the number given

- ⊗ **DON'T EXPLAIN THE CONDITION**
- ✓ **DO EXPLAIN THE REALITY OF LIVING WITH THE CONDITION**

Are you isolated at home, unable to prepare meals or did a family member have to give up work to care for you? Specific information about the impact on daily life is more useful than saying 'difficult managing side effects'.



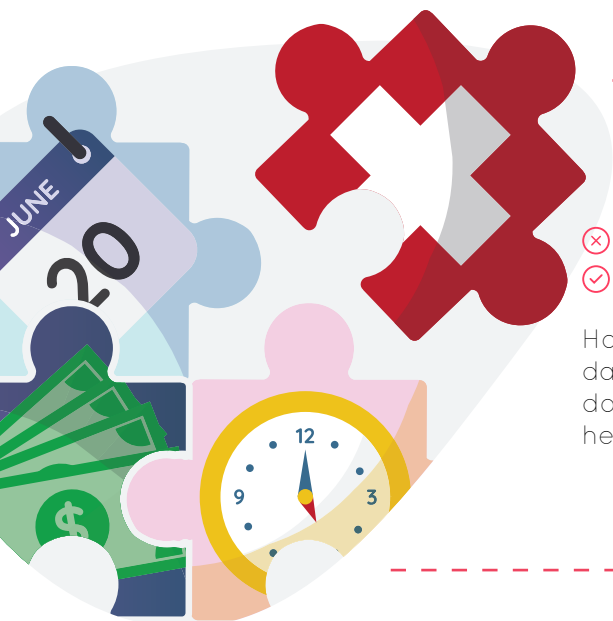


- ⊗ DON'T EXPLAIN THE TREATMENT
- ✔ DO EXPLAIN THE REALITY OF HAVING (OR NOT HAVING) TREATMENT

In what specific way do you think the new treatment will make life better for you? If you're already using the treatment, what has been your experience? If you're funding it yourself, what is the cost of that (financial and other costs)?

- ⊗ DON'T SUBMIT CLINICAL DATA
- ✔ DO SUBMIT WHAT HAPPENS IN THE REAL WORLD

If you represent a patient group or community, do you have information about your members' experiences, pathways, preferences, or unmet needs? Consider collecting information or partnering studies that answer the questions that matter to you.



- ⊗ DON'T SUBMIT PUBLISHED LITERATURE AND STATS
- ✔ DO SUBMIT THE NUMBERS THAT MATTER TO YOU

How many nights do you spend in hospital each year? How many days do you take off work for medical appointments? How long does it take you to get ready to go out? Numbers like these can help others better understand how a treatment might benefit you.

- ⊗ DON'T HOLD YOURSELF RESPONSIBLE
- ✔ DO WHAT MATTERS MOST

You may be able to submit useful information to PBAC, but there are no guarantees you will get the outcomes you seek. This is because PBAC advice is always formed from multiple sources of information - including clinical and cost effectiveness evidence - never one input. Patient voices can be valuable input, but being involved can be stressful. Your right not to get involved or stop being involved is respected.

