



**Australian Government**

**Department of Health**

# **Consultation Survey on MSAC Application 1628**

## **Alpha-1-Antitrypsin Genotyping**

This feedback survey relates to the application form and Population, Intervention, Comparator and Outcome (PICO) Confirmation for new and amended requests for public funding (including but not limited to the Medicare Benefits Schedule (MBS)).

Please use this template, to prepare your feedback on the application form and/or the PICO Confirmation. You are welcome to provide feedback from either a personal or group perspective for consideration by the Department of Health when the application is being reviewed.

The data collected will be used to inform the Medical Services Advisory Committee (MSAC) process to ensure that when proposed healthcare interventions are assessed for public funding in Australia, they are patient focused and seek to achieve best value.

This feedback survey should take approximately 15 minutes to complete.

You may also wish to supplement your responses with further documentation or diagrams or other information to assist the Department in considering your feedback.

Thank you for taking the time to provide valuable feedback.

**Responses may be provided to the MSAC, its subcommittees, a health technology assessment group and the applicant. Should you require de-identification please contact the HTA team (details below).**

While stakeholder feedback is used to inform the application process, you should be aware that your feedback may be used more broadly by the applicant.

**Please reply to the HTA Team:**

**Email: [HTA@health.gov.au](mailto:HTA@health.gov.au)**

**Postal: MDP 959 GPO 9848 ACT 2601**

## PART 1 – PERSONAL AND ORGANISATIONAL INFORMATION

### 1. Respondent details

Name: Patricia Schluter

Email: patricias@lungfoundation.com.au

Phone No: 0433396855

### 2. (a) Is the feedback being provided on an individual basis or by a collective group? (please select)

Collective Group

**(b) If individual, specify the name of the organisation you work for**

**(c) If collective group, specify the name of the group**

### 3. How would you best identify yourself?

Other

**(a) If other, please specify**

## PART 2 – CLINICAL NEED AND PUBLIC HEALTH SIGNIFICANCE

4. Describe your experience with the medical condition (disease) and/or proposed intervention and/or service relating to the application form

Lung Foundation Australia represents the views of patients, clinicians and researchers. Our policies, services, research and advocacy activities are developed with and for, people living with respiratory conditions, their families and carers, and respiratory clinicians and researchers.

5. What do you see as the benefit(s) of the proposed medical service, in particular for the person involved and/or their family and carers?

The proposed service will provide a timely, definitive diagnosis of AAT deficiency as well as the genetic cause of that deficiency in one test. Patients receiving early clarity on the cause of AATD have an opportunity to make informed lifestyle and health choices to optimise their, and their families, well-being and longevity. We support the claims made in the application.

6. What do you see as the disadvantage(s) of the proposed medical service, in particular for the person involved and/or their family and carers?

The only *potential* disadvantage with the service, is not the knowledge it would confer on individuals, but rather the risk that there will be no psychological support whilst waiting for the result, or after the result.

7. What other benefits can you see from having this intervention publically funded on the Medicare Benefits Schedule (MBS)?

Early diagnosis of disease is proven to reduce (and delay) presentations to public hospitals services, because knowledge facilitates informed management of disease and health choices. Furthermore, access to life-saving and life-changing diagnostic tests - which impart knowledge - appropriately subsidised by the Australian government, ensures the overall health of the Australian community. When our most vulnerable members are supported to live with optimal health and well-being, we achieve the highest possible level of collective community health.

8. What other services do you believe need to be delivered before or after this intervention, eg Dietician, Pathology etc?

Lung Foundation recommend that whilst waiting for the results of the test, patients and their immediate carers and family be provided/referred to support services (such as counselling) and evidence-based information to manage anxiety, uncertainty and fear.

After patients receive test results, Lung Foundation Australia recommend that, if required, patients, carers and family members are supported with easy access to ongoing psychological support (including genetic, reproductive and lifestyle counselling) and information on any conditions disclosed by the testing. Patients must have access to appropriate medical and non-medical interventions (such as exercise programs) related to any conditions disclosed by the testing.

## PART 3 – INDICATION(S) FOR THE PROPOSED MEDICAL SERVICE AND CLINICAL CLAIM

9. Do you agree or disagree with the proposed population(s) for the proposed medical service as specified in Part 6a of the application form?

Strongly Agree

Specify why or why not:

We agree with the proposed population, but note that the proposed test, is a “second-line” test – that is, it is recommended after a serum test for AAT has identified a deficiency. We note that serum testing is not highly sensitive, and further note that it is estimated that less than 10% of people with AATD are diagnosed. We recommend that consideration be given to reviewing and broadening the eligible proposed population 12 months after it has become available.

10. Have all the associated interventions been adequately captured in Part 6b of the application form?

Yes

(a) Please explain:

11. Do you agree or disagree that the comparator(s) to the proposed medical service as specified in Part 6c of the application form?

Strongly Agree

The current phenotyping test (IEF) is the most appropriate comparator. And indeed, is inferior to the proposed genotype test. This is a matter of replacing old technology with improved technology.

12. Do you agree or disagree with the clinical claim made for the proposed medical service as specified in Part 6d of the application form?

Strongly Agree

Specify why or why not:

The application is based on strong, well-established evidence.

## PART 4 – COST INFORMATION FOR THE PROPOSED MEDICAL SERVICE

13. Do you agree with the proposed MBS item descriptor, as specified in Question 53 of the application form?

Strongly Agree

**Specify why or why not:**

Lung Foundation Australia agrees with the strong evidence presented by the applicants, and further notes the views of the Thoracic Society of Australia and New Zealand in their position statement, *Diagnosis and treatment of lung disease associated with alpha one-antitrypsin deficiency: A position statement from the Thoracic Society of Australia and New Zealand*, that IEF testing will be surpassed by AAT genotyping as this technology becomes more readily available.

14. Do you agree or disagree with the proposed MBS fee, as specified in Question 53 of the application form?

Agree

**(a) Specify why or why not:**

Lung Foundation Australia note the proposed fees of \$100.00 for the initial gene panel testing and \$260 for subsequent (if required or ordered) sequencing of the SERPINA 1 gene. We further note that the likely take-up of this testing across the Australian population is limited and that due to the accuracy of these tests, they would be a once-in-a-lifetime test for an individual. We believe this fee proposal adequately reflects the balance between funding a sustainable community health system for all Australians and individual ability to contribute to the cost of their services.

## **PART 5 – ADDITIONAL COMMENTS**

**15. Do you have any additional comments on the proposed intervention and/or medical condition (disease) relating to the proposed medical service?**

PLEASE SEE ATTACHED SURVEY WHICH REFLECTS THE VIEWS OF LUNG FOUNDATION PATIENTS & CLINICIANS.

**16. Do you have any comments on this feedback survey? Please provide comments or suggestions on how this process could be improved.**

**Again, thank you for taking the time to provide valuable feedback.**