

Response ID ANON-VV54-Y14D-Q

Submitted to Public Consultation on the refresh of the National Strategic Framework for Chronic Conditions
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Introduction

Privacy Notice

Demographics

1 Which stakeholder group best describes you? Please tick all that apply.

National not for profit non-government organisation

Part 1: Overview of the Framework

2 Have you engaged with and used the Framework, and if so, how? Please tick all that apply. There is also the option to include any other information about your engagement with the Framework in the 'Other' open-text response box.

I, or the organisation I represent, have not utilised the Framework in any capacity

(Optional) Other::

ASCIA (Australasian Society of Clinical Immunology and Allergy) has not used the Framework, as the following immune system disorders are not currently collected in the Census and are not listed as chronic conditions, yet they fit with the Framework's definition of chronic diseases:

1. Allergic diseases (including food, drug, insect and respiratory allergies) are chronic conditions that affect 1 in 5 Australians, have a significant impact on quality of life, and can be life threatening due to severe allergic reactions (anaphylaxis).
2. Primary immunodeficiency diseases (also know as inborn errors of immunity) are potentially serious, chronic illnesses due to inherited absence or dysregulation of parts of the immune system, that can lead to reduced quality of life and life expectancy.

References:

<https://nationalallergycouncil.org.au/about-us/our-strategy>

<https://www.nationalimmunodeficiencystrategy.org.au/immunodeficiency-strategy>

Part 1: Overview of the Framework

3 The Vision of the Framework (Vision) is: "All Australians live healthier lives through effective prevention and management of chronic conditions."

Question 3A - To what extent do you agree the Vision is still relevant?:

Agree

(Optional): Please provide further comments about your response, including any suggested amendments to the Vision.:

The Vision of the Framework aligns with the following national strategies developed by ASCIA (in collaboration with patient/carer organisations and other stakeholders):

1. National Allergy Strategy Purpose - To improve the health and quality of life of Australians with allergic diseases and minimise the burden of allergic diseases on individuals, their carers, healthcare services and the community.
2. National Immunodeficiency Strategy Purpose- To improve the health and wellbeing of people living with primary immunodeficiency diseases and minimise the burden on individuals, carers, health services and the community.

References:

<https://nationalallergycouncil.org.au/about-us/our-strategy>

<https://www.nationalimmunodeficiencystrategy.org.au/immunodeficiency-strategy>

Part 1: Overview of the Framework

4 Please provide a score from 0-10 to demonstrate how important you think each of the enablers are (with 0 being not at all important and 10 being very important).

Question 4A - 1. Governance and leadership — supports evidence-based shared decision-making and encourages collaboration to enhance health system performance.:

10

Question 4A - 2. Health workforce — a suitably trained, resourced and distributed workforce is supported to work to its full scope of practice and is responsive to change.:

10

Question 4A - 3. Health literacy — people are supported to understand information about health and health care and appropriate health care settings, to apply that information to their lives and to use it to make decisions and take actions relating to their health.:

10

Question 4A - 4. Research — quality health research accompanied by the translation of research into practice and knowledge exchange strengthens the evidence base and improves health outcomes.:

10

Question 4A - 5. Data and information — the use of consistent, quality data and real-time data sharing enables monitoring and quality improvement to achieve better health outcomes.:

10

Question 4A - 6. Technology — supports more effective and accessible prevention and management strategies and offers avenues for new and improved technologically driven initiatives.:

10

Question 4A - 7. Resources — adequate allocation, appropriate distribution and efficient use of resources, including funding, to address identified health needs over the long-term.:

10

(Optional): Are there any other enablers you think should be included in the Framework?:

Yes, the following enablers should also be considered:

1. Multidisciplinary teams - A range of health professionals should be upskilled and resourced to work in collaboration to improve patient care.
2. Access to care - Health professionals working in regional areas should be upskilled and resourced to enable people in regional, rural and remote areas to access quality healthcare.

Part 2: Objectives of the Framework

5 Please discuss which, if any, of the above determinants of health have most significantly impacted you or the work of your organisation. Additionally, are there any other determinants of health that you think the Framework should focus on? If yes, please note them.

(Optional)::

The main barriers to care for people with allergic diseases include long waiting times to see a specialist in the public system, costs of accessing private specialist services, limited service availability (particularly in rural, regional and remote areas), and limited knowledge of health professionals who have not had additional training.

The main barriers to care for people with primary immunodeficiency diseases include delayed recognition of signs/symptoms, delayed diagnosis, access to appropriate testing (such as genomic tests), access to appropriate and funded treatments, limited service availability (particularly in rural, regional and remote areas), and limited knowledge of health professionals who have not had additional training.

Part 2: Objectives of the Framework

6 To what extent do you agree with the following statements?

Question 6A - Australians with chronic conditions can easily access primary care services, including regular care with a GP and/or allied health providers.:
Somewhat agree

Question 6A - Australians with chronic conditions can easily access specialty healthcare services when required.:
Somewhat disagree

(Optional): Please provide further comments about any of your responses to the previous statements.:

GPs and allied health professionals have limited knowledge of allergic diseases and primary immunodeficiency diseases, unless they have had additional postgraduate education and training in allergic diseases and primary immunodeficiency diseases. This is partly due to limited education in these areas in undergraduate medical and allied health degrees.

People with allergic diseases and primary immunodeficiency diseases who live in regional, rural or remote locations have limited access to specialist medical services, as most clinical immunology/allergy specialists are located in capital cities.

Part 2: Objectives of the Framework

7 To what extent do you agree with the following statement?

Question 7A - I have access to health information and data, and use this to help make decisions regarding the prevention, diagnosis, treatment and management of chronic conditions.:

Disagree

(Optional): Please provide further comments about your response, and if appropriate, provide examples of ways you have or have not used information and data.:

There is limited data collected about allergic rhinitis, and data about other allergic diseases and primary immunodeficiency diseases is very limited. Information collected about allergic diseases and primary immunodeficiency diseases would provide important data to inform strategies to enable early recognition, diagnosis, management and appropriate treatments.

Part 2: Objectives of the Framework

8 To what extent do you agree with the following statements?

Question 8A - 1. Australians living with chronic conditions, including myself, friends/family, patients, or members of the organisation I represent if applicable, are recognised in the Framework.:

Somewhat agree

Question 8A - 2. The Framework is representative of the diversity of population groups in Australia.:

Somewhat agree

Question 8A - 3. The Framework recognises the individual needs of the many different groups in Australia.:

Somewhat agree

Question 8A - 4. The Framework provides guidance about how the prevention and management of chronic conditions can be tailored to the needs of different population groups.:

Somewhat agree

(Optional): Please provide further comments about any of your responses to the previous statements.:

The framework should be refreshed to include allergic diseases and primary immunodeficiency diseases as chronic conditions, as these are not currently listed, and affect a significant proportion of Australians.

Part 2: Objectives of the Framework

9 Please provide information known to you on the experiences of people with chronic conditions in the above, or additional, priority population groups including any challenges and barriers in accessing prevention and/or treatment services that you think may be of relevance to the refresh of the Framework.

(Optional)::

The Framework does not include people with the following immune system disorders, which are chronic conditions that are often inherited and are usually lifelong:

1. Allergic diseases
2. Primary immunodeficiency diseases

Early recognition and diagnosis leads to appropriate management and treatments, which enable people with these immune system disorders to lead healthy and productive lives.

In contrast, delayed recognition and diagnosis of these immune system disorders can significantly increase medical costs (for the individual and healthcare system), reduced productivity, reduced quality of life and reduced life expectancy.

Therefore it is important that these immune system disorders are listed in the refreshed Framework as chronic conditions.

Part 3: Focus on the Future

10 Potential barriers for people with chronic conditions are shown below. Which of these barriers do you believe significantly impact Australians living with chronic conditions (including yourself if applicable)? Please select all that apply.

Difficulty in finding an appropriate healthcare provider or facility, Long wait lists, Lack of coordinated care and communication between health professionals, Lack of information sharing and exchange between healthcare providers, Financial cost of healthcare, Limited awareness and understanding of chronic conditions and/or prevention by patients and/or carers, Limited understanding of the healthcare system by patients and/or carers, Limited knowledge of some chronic conditions by healthcare professionals, Not being able to attend appointments due to geographical location/transport, Lack of health promotion education and prevention activities, Low English proficiency and other language challenges, Limited availability of publicly funded health programs, Lack of access to research and data

(Optional): Are there any other barriers that you would like to draw attention to?:

The barriers listed above could be addressed for immune system disorders by:

1. Adding allergic diseases and primary immunodeficiency diseases as chronic conditions in the refreshed Framework.
2. Implementing national strategies that have been developed by ASCIA, the peak professional body for clinical immunology and allergy in Australia and New Zealand, working together with relevant patient/carer support organisations:
 - a) National Allergy Strategy - currently being implemented (funded by the Australian Government) by ASCIA and Allergy & Anaphylaxis Australia (A&AA) as partners in the National Allergy Council.
 - b) National Immunodeficiency Strategy - currently being implemented, but not yet funded by the Australian Government.

Part 3: Focus on the Future

11 Do you support this description of the inter-relationship between the Framework and condition specific Action Plans and Strategies?

Yes

(Optional): Please elaborate on your response.:

There is currently no integration of the following national strategies that have been developed by ASCIA, the peak professional body for clinical immunology and allergy in Australia and New Zealand, working together with relevant patient/carer support organisations:

a) National Allergy Strategy - currently being implemented (funded by the Australian Government) by ASCIA and Allergy & Anaphylaxis Australia (A&AA) as partners in the National Allergy Council.

b) National Immunodeficiency Strategy - currently being implemented, but not yet funded by the Australian Government.

These strategies include action plans but as they are not integrated with the Framework, implementation is more challenging. Integrating these actions into a refreshed Framework would contribute to improved health outcomes for more than 1 in 5 Australians and reduce overall healthcare costs.

Part 3: Focus on the Future

12 Do you support this approach?

Yes

(Optional): Please elaborate on your response.:

ASCIA supports this approach if allergic diseases and primary immunodeficiency diseases are included as chronic conditions in the refreshed Framework. We expect that this approach will improve health outcomes by supporting collaborations, improving efficiency and reducing duplication.

Part 3: Focus on the Future

13 Do you believe a focus on these common issues is relevant, accurate and appropriate for Australians living with a chronic condition?

Yes

(Optional): Please elaborate on your response and/or include any other common issues across chronic conditions that you would like to note.:

Multi-disciplinary care - Management of people with allergic diseases and primary immunodeficiency diseases can be complex, which requires specialist medical and nursing care, as well as multi-disciplinary care, to prevent complications and disabilities and improve health outcomes.

Managing multimorbidity - People with allergic diseases can have multiple allergic conditions and people with primary immunodeficiency diseases can have frequent or severe infections, swellings and autoimmune problems.

Continuity of care across life stages - Allergic diseases and primary immunodeficiency diseases often begin in childhood and are often lifelong, so transition from paediatric to adult medical care is important to ensure continuity of care.

Health promotion and education is required to empower patients and carers to self-manage their conditions with support from medical teams.

Embedding prevention is important for allergic diseases and primary immunodeficiency diseases.

Part 3: Focus on the Future

14 Please provide information on any opportunities for digitisation to enhance the prevention, treatment and management of chronic conditions.

(Optional)::

Increased use of electronic records has the potential to enhance prevention, treatment and management of chronic conditions, including allergic diseases and primary immunodeficiency diseases.

Online resources, training modules, tools and guidelines have already been developed to support the prevention, treatment and management of allergic diseases and primary immunodeficiency diseases, but these require regular review and updating, as well as widespread promotion to make an impact on education and training in these conditions,

Part 3: Focus on the Future

15 Please describe any impacts (positive or negative) of COVID-19 that you would like to highlight.

(Optional)::

The increased use of telehealth, electronic prescriptions and video meetings due to the COVID-19 pandemic has improved access to medical care for some patients and opportunities for hybrid educational meetings for health professionals.

However there have been some negative impacts:

1. Reduced in-person consults can result in delayed recognition and diagnosis of conditions.

2. Not all conditions can be managed using telehealth, particularly complex cases.

3. Multidisciplinary care and collaborations are limited in virtual settings.

Part 3: Focus on the Future

16 Which of the following statements are most important to you in terms of how the Australian Government enhances and uses the Framework in the future? Please select up to 5 options.

Increased focus on how organisations can work together to improve the management of chronic conditions, Refresh the content of the Framework to be better aligned with other state and territory, national and international policies, strategies and plans, Refresh the content of the Framework so it reflects the post COVID-19 health landscape

Part 4: Summary

17 In 1000 words (6000 characters) or less, please provide any additional feedback on the Framework including any other opportunities to improve the Framework.

(Optional): :

ASCIA welcomes the opportunity to provide feedback on the Framework, and would support the refreshing, and promotion of the Framework if:

1. Immune system disorders (allergic diseases and primary immunodeficiencies) are included as chronic conditions.
2. Current national allergy and immunodeficiency strategies developed by ASCIA (with national patient/carer organisations) are integrated into the refreshed Framework.
3. National health promotion campaigns include immune system disorders (allergic diseases and primary immunodeficiencies).